DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) Systematic Literature Review: Men's experiences of disclosing childhood sexual abuse in adulthood: a qualitative meta-synthesis; 2) Service Improvement Project: Development of an online roadmap of psychological support in collaboration with mental health service users; 3) Main Research Project: Data-gathering style in individuals with autism spectrum conditions: an examination of its relationship with paranoia using the beads task.

Bennert, Kristina

Award date:
2017

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Research portfolio submitted in part fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

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Kristina Bennert

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University of Bath

Department of Psychology

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MAIN RESEARCH PROJECT

Abstract for Service Improvement Project

Background: There is growing recognition of the potential of *e-mental health* to contribute to the delivery of mental health services. There are strong moral, political and health-economic arguments for involving service users in the development of mental health services.

Aims: This paper describes a Service Improvement Project carried out within a Community Mental Health Service to bridge the gap between availability of online psychological resources and service users' information needs about psychological support. Iterative development of a facilitative gateway - the 'Online Roadmap of Psychological Support' was carried out in collaboration with service users and other stakeholders.

Methods: Development proceeded in three phases: (1) stakeholder consultation (2) feasibility study, including assessment of service user information needs and preferences; (3) discussion of findings to generate ideas for implementation and evaluation. Methods of data collection included informal interviews, focus groups and a postal survey.

Results: Recommendations for the Online Roadmap were shared with key decision-makers and guided implementation as part of wider website redesign. The new service website provides accessible information about psychological support alongside service user narratives and hyperlinks to external psychological resources covering a range of mental health difficulties.

Conclusion: The project illustrates how mental health services can harness the potential of e-mental health to meet service users' information needs regarding psychological support within their local services and beyond. The discussion reflects on possible tensions between the constraints of statutory mental health services and the empowerment of service users as experts-by-experience.

Keywords: e-mental health, online resources, service user involvement, psychological support, mental health service improvement

Abstract for Systematic Literature Review

Background: Around 8% of men are estimated to experience childhood sexual abuse (CSA), but less is known about the male survivors' experiences compared to females. Over the past two decades, a small stream of qualitative studies has started to explore men's experiences of disclosing CSA in adulthood, but most studies are based on small and selective samples.

Methods: Meta-synthesis provides a method for combining findings from original qualitative research to generate new understandings of a phenomenon that is greater than the sum of its parts. This paper article presents a systematic review and meta-synthesis of peer-reviewed qualitative research on men's experiences of disclosing childhood sexual abuse in adulthood. Systematic searches were conducted on six databases and 927 abstracts retrieved for screening.

Results: 20 studies, published from 1996 - 2016, were included in the review. Studies examined barriers and facilitators of disclosure and the impact of disclosure and non-disclosure in adulthood. Meta-synthesis of first- and second-order themes resulted in third-order constructs that suggest an understanding of (non-)disclosure as a communicative acts which constitutes a discursive re-positioning within a contested space characterised by competing discourses on masculinity, generational and gender roles and relationships.

Conclusions: Limitations of the meta-synthesis and directions for future research are discussed.

Keywords: childhood sexual abuse, male survivors, disclosure, qualitative methods, systematic review

Abstract for Main Research Project

Individuals with Autism Spectrum Conditions (ASC) have been found to experience higher levels of paranoia than the general population. However, cognitive mechanisms involved in its development and maintenance may differ from those suggested for typically developed individuals with persecutory ideation. A reasoning bias in the form of reduced data-gathering ('jumping-to-conclusions', or JTC bias) has been proposed as a contributory factor for paranoia in people with psychosis and non-clinical populations. Data-gathering style was investigated in 39 adults with ASC and 64 typically developed controls using two probabilistic reasoning tasks: the beads task and an emotionally salient equivalent. Despite higher levels of paranoia, the ASC group requested more information and were less likely to show a JTC bias than the typically develop group. Results suggest that data-gathering style may not be a contributory factor for paranoia in autism, consistent with the proposal of a differential cognitive structure of paranoia in individuals with ASC.

Keywords: autism, paranoia, jumping to conclusions, reasoning bias, decision-making

Executive Summary of Main Research Project

Data-Gathering Style in People with Autism and Its Relationship with Paranoia

Paranoia exists on a spectrum of severity in the general population. Many people hold a few paranoid beliefs, but people with Autism Spectrum Conditions have been found to experience higher levels of paranoia than most typically developed people. Social anxiety, which is associated with paranoia, has been found to occur in around half of all adults with autism.

Psychological models of paranoia have identified attention and thought processes, beliefs, ways of reasoning and meaning-making which may contribute to the development and maintenance of paranoia. These psychological processes involved in the formation of paranoid ideas have been well-studied in people with psychosis and schizophrenia: they include a tendency to make decisions more hastily and on the basis of incomplete information. This tendency is referred to as "reduced data-gathering" and, in its most extreme form, has been referred to as the 'jumping to conclusions' bias.

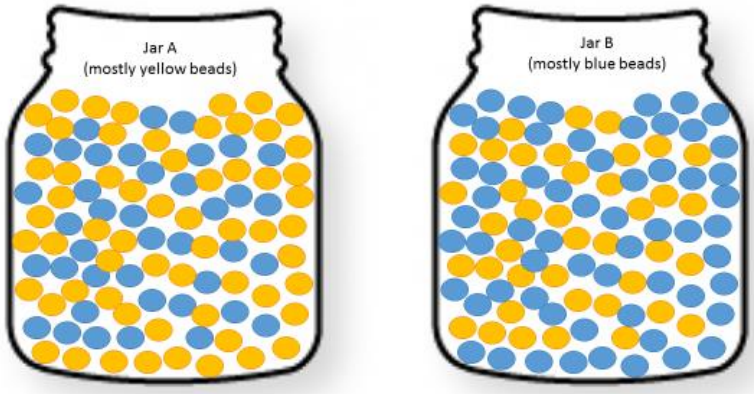

Figure A: Yellow and Blue Beads in Ratios of 60:40 and 40:60 Beads

Data-gathering style and the 'jumping to conclusions' bias has typically been investigated using a task known as the Beads Task. This task involves making decisions under conditions of uncertainty. In the Beads Task, participants are shown a series of blue and yellow beads and are asked to decide which of two jars containing different

proportions of blue and yellow coloured beads (Figure A) the beads are likely to have come from. Participants can ask to see as many beads as they like, up to a maximum of twenty beads, before making a decision.

Some researchers have also used a task known as the Survey Task, which has the same logical structure as the Beads Task but uses emotionally-laden words instead of neutral beads, namely positive and negative words used to describe people in a survey (Figure B).

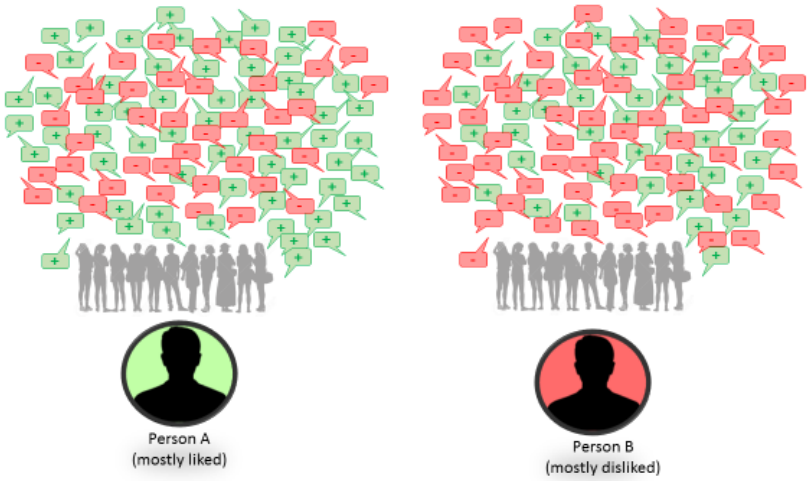

Figure B: Visual Representation of the Survey Task

Previous research has shown that people with paranoia and strongly held beliefs that they are being persecuted will ask to see fewer beads than people without mental health problems. Around two thirds of people with psychosis will request fewer than three beads. Psychological interventions based on the principles of cognitive behavioural therapy have been developed to target the 'jumping to conclusions' bias and have shown some success in correcting a reduced data-gathering style in people with schizophrenia.

However, we don't yet know whether the psychological mechanisms that contribute to paranoia in autism are similar or different to those in psychosis, and whether people with autism and high levels of paranoia will also show the 'jumping to conclusions' bias. A limited amount of research has looked at reasoning and data-gathering style in people with autism and has found that they tend to gather more information than typically developed individuals before reaching decisions. In other words, they show the opposite pattern to jumping-to-conclusions. One study used the

Beads Task as described above and found that people with autism asked to see more beads than a group of typically developed individuals. Another study also used the Beads Task and found that people with autism asked to see fewer beads than typically developed individuals and that one third of people with autism showed the jumping to conclusions bias and requested fewer than three beads.

This study aimed to replicate aspects of the two conflicting studies to examine reasoning style in people with autism in relation to levels of paranoia and to gain greater clarity over whether people with autism 'jump to conclusions' under uncertain conditions.

103 individuals were recruited via social media and autism-specific websites and mailing lists. 39 people with autism and 64 typically developed controls took part in an online survey and completed a series of questionnaires, which asked about autism traits, symptoms of paranoia and social anxiety, and the Beads and Survey Tasks as described above. Data were analysed with statistical methods and produced the following findings:

- People in the autism group on average had higher levels of paranoia and social anxiety than the typically developed group.
- People with autism on average asked to see more beads from a jar and words from a survey than the typically developed group.
- Typically developed individuals were more than four times more likely to 'jump to conclusions' than people with autism on at least one of the two tasks.
- The nature of task materials (i.e. neutral versus emotionally laden materials) did not seem to affect participants' performance on the tasks, with no difference in the average numbers of beads requested by individuals in each group.
- Paranoia was not found to be related to asking for fewer beads or words, i.e. reduced data-gathering, in either group.
- Higher scores on the autism trait of 'systemising' was not related to asking for a greater number of beads or words, i.e. increased data-gathering, as had been found in a previous study.
- Participants with autism did not differ significantly from typically developed individuals in the level of confidence they had in their decision, the time they took to complete the tasks, or the likelihood of choosing the logically correct jar.

The study had several methodological limitations, such as groups being unevenly matched in terms of age, gender and co-morbid mental health problems. Differences in IQ were not assessed and classification of participants as ASC or typically developed relied on self-report. However, participant numbers and methods of measurement were robust and analysis produced statistically significant and clinically meaningful differences in outcomes.

It was concluded that reduced data-gathering style may not be involved in the development and maintenance of paranoia in people with autism. Instead, it may have different origins and may be experienced in qualitatively different ways from paranoia in typically developed individuals. More research is needed to understand these differences better and to gain insights that can help to adapt existing psychological therapies for paranoia for people with autism spectrum conditions.

Connecting Narrative

After completing a PhD in Language and Communication Research in 2000, I had spent the last 14 years before starting clinical training working as a researcher in academic health services research on projects designed by other people. Consequently, the opportunity to finally design and execute my own research projects brought about feelings akin to the proverbial child in a sweet shop. My excitement and enthusiasm, combined with a lack of clarity about how much, or rather, how little, time would be dedicated to the research component of the course, made me want to cram as many sweets as possible into what turned out to be rather small pockets. In hindsight, my initial visions of what could be achieved, in particular with regard to my service improvement project, were clearly over-ambitious. Nevertheless, conducting the projects has been an extremely satisfying, if, at times, rather stressful, experience, and it was a privilege to be working with such knowledgeable and supportive supervisors. While there were a few changes en route from my initial research plans to their final destinations, I feel pleased with what it has been possible to achieve within the time available and the small but hopefully meaningful contribution I have been able to make, with the help of lots of other people, in each of my chosen areas of research.

The two main therapeutic orientations of the Bath course are Cognitive Behavioural Therapy (CBT) and Systemic Therapy (ST). The ethos of the course reflects the core values of the NHS. It is committed to evidence-based and patient-centred practice, equality, diversity and the destigmatising and normalisation of mental distress through its psychological formulation. My choice of research projects has aimed to reflect these theoretical orientations and values.

Service Improvement Project

During my time as a postdoctoral researcher, I had worked on a number of projects with the Health Experiences Research Group at the University of Oxford, which resulted in the production of modules for the *HealthTalk* website (http://www.healthtalk.org/). *HealthTalk* provides free, reliable information about a broad range of physical and mental health issues, by sharing people's real-life experiences. The website presents peer testimony in the form of video- and audio-clips of

excerpts from rigorous research interviews with patients, which are integrated with research summaries and hyperlinked to factual information and resources (Kidd & Ziebland, 2016). The website has been accredited by the Information Standard and has won multiple awards for its role in empowering patients to feel more confident in managing their healthcare needs and their encounters with healthcare professionals.

During my time as a researcher at the School of Social and Community Medicine at Social Bristol University, I had listened to my academic colleagues presenting promising results for computerised psychological interventions and self-help tools in the context of randomised controlled trials, but I was also aware of the low rates of uptake of these applications in clinical practice.

When I joined the North Bristol Complex Psychological Interventions (CPI) team on my initial Working Age Adults placement in October 2014, I was struck by the team's dilemmas in the wake of recent service recommissioning to create a psychologically informed environment at all levels of the service and to ensure equitable access to psychological interventions with extremely limited staff resources. In particular, the CPI team felt that the scope of and consistency of indirect working and psychology referral practices needed improvement, as did knowledge about types of psychological interventions available within the service amongst community mental health staff and service users. In my mind, the possibilities of the internet for psycho-education and the proliferation of freely available e-mental health tools in recent years provided possible solutions to some of these challenges. I envisaged that a website structure akin to the *HealthTalk* model, with narratives from local service users about their experience of psychological support scaffolding new service users' engagement with online resources, could bridge the gap between e-mental health tools and lack of uptake. However, I felt it was crucial to involve service users in any service improvement activities in this area, to ensure that resulting changes would be experienced as feasible, acceptable and empowering from their points of view.

At the time, my placement supervisor Julie Wilkinson was chairing a Service User Reference Group, which was set up as part of the recommissioning process, so this provided a way in for me to collaborate with a small group of highly motivated individuals and explore their priorities and ideas for service improvement alongside those of the CPI team.

Initial idea development and co-design with the reference group of a questionnaire to explore information needs and preferences about psychological therapies and other forms of support among a broader sample of Bristol Mental Health service users proceeded quickly and smoothly. The group also gave feedback on drafts of consent forms, information sheets and an interview schedule to collect audio/video-recorded narratives about experiences of psychological support from local service users. I was lucky to find an enthusiastic collaborator in the service's newly appointed Communications Officer, who helped me think through the technical possibilities for evaluating the potential impact of service improvement. However, due to bureaucratic constraints on handling and storing audio- and video materials within the trust, cuts in funding and staff changes within the service, as well as time pressures on my part, it was not possible for me to gather and collate service user narratives myself as had originally been planned. After an eight month lull in activities due to the lack of a dedicated service-internal contact for the SIP, the appointment of a new Communications Officer in May 2016 meant that the final phase of the SIP could get re-started with several modifications to the original plans. Instead of collecting additional materials, it became possible to include service user narratives that had been produced for other purposes within the hyperlink structure of the new service website. In a series of meetings and focus groups, we were able to negotiate, how the recommendations emerging from the SIP could best be integrated and accommodated within the existing structures of the larger service website. This led to a distribution of the original components into separate web sections and made it difficult for their uptake to be independently evaluated. While it was disappointing that the SIP could not be implemented with full conceptual integrity, there were also considerable benefits of it becoming part of a larger structure, such as regular posts and email updates about news aspects of the website issued by the Communications Officer to Bristol Mental Health service users.

Overall, I feel very pleased that the SIP recommendations contributed to the service's website structure and contents in ways that will hopefully be experienced as user-friendly, destigmatising and empowering by service users, that can improve the understanding of mental health difficulties and evidence-based psychological interventions amongst service users and the wider public alike, and that may also help to raise the profile of psychological work within the Trust.

Systematic Literature Review

For my literature review, I wanted to choose a topic that I could develop within a systemic perspective. Through personal and clinical experiences, I had become interested in the intergenerational transmission of mental health difficulties and cycles of violence and abuse.

I developed a proposal for a critical literature review of research into children's experiences of growing up with a parent with severe mental illness, with Attachment Narrative Therapy (Dallos, 2006; Dallos & Vetere, 2012; Vetere & Dallos, 2008) providing a conceptual framework for synthesising the available research evidence. The proposal was passed by the course, but when I repeated the systematic search process a few months later, I discovered that not just one, but two research syntheses on the topic of children's experiences of parental mental illness had been published in the intervening months.

In search of a new focus for my literature review, my placement experiences of working with clients with complex development trauma and my reading of two inspiring books on the subject - Judith Herman's (2015) 'Trauma and Recovery', originally published in 1992, and Bessel van der Kolk's (2014) - led me to review the literature on intergenerational patterns of child sexual abuse (CSA). I discovered that while the impact and experience of female CSA is a well-researched topic, there was a relative dearth of literature on male CSA. Existing studies seemed to suggest that male CSA was vastly under-reported and that many adult survivors continued to suffer in silence due to a culture of taboo and denial, similar to the one that had been described by Judith Herman in relation to female child sexual abuse and domestic violence a quarter of a century earlier. Furthermore, there appeared to be very little qualitative research on men's experiences of disclosing sexual abuse in adulthood to further an understanding of the potential barriers and facilitators to disclosure. Existing studies had small, selective samples and often reported only on a narrow range of issues. I felt that these factors made the area a worthwhile topic for a qualitative meta-synthesis.

My previous experience of working as a qualitative researcher and appraising qualitative literature made me feel competent to carry out this work, even though I did

not have access to a team of colleagues with whom to discuss and develop emergent themes as is customary in qualitative meta-synthesis. My project supervisor Catherine Butler and my fellow trainee Lucy Fiddick help me to implement rigorous methods by helping out with discussion of themes and screening of abstracts and full texts, respectively. The process of synthesising the identified studies felt emotionally draining, but the use of qualitative analysis software helped me to keep track of the large amount of data and to carry out the recoding of original themes in an orderly and systematic fashion. I hope that the literature review and meta-synthesis will contribute to a better understanding of the specific concerns that exist for male survivors of CSA in disclosing their experiences and that this can help to improve clinical and therapeutic practice and development of support services accessible to men.

Main Research Project

Coming from a research background, I have valued CBT as a therapeutic approach with a firm evidence base in empirical research on the involvement of specific cognitive mechanisms in the development and maintenance of mental health difficulties. I was keen for my main project to contribute to this evidence base in some small way. I was also keen for the project to have an experimental component instead of being purely based on self-report measures.

Before starting training, I had worked as a local researcher on a large multicentre RCT of citalopram for negative symptoms of schizophrenia. This job involved many home visits to people with a diagnosis of schizophrenia, who had been identified by their care co-ordinators as experiencing negative symptoms, in order to assess their eligibility for the trial. It made me acutely aware of the poor quality of life, isolation and lack of social engagement experienced by this patient group. Reading Richard Bentall's book 'Madness Explained' (2004) during my first term on the course and learning about experimental research on attentional and attributional biases in Bipolar Disorder to examine the hypothesis of mania as a defence to depression gave me the idea for a project to explore asociality in patients with negative symptoms of schizophrenia as a defensive reaction to experiences of social rejection and exclusion - an idea that had already been put forward in previous research by Paul Grant and Aaron Beck (2009, 2010). With the support of

Lorna Hogg as an academic supervisor, I developed a full research proposal which was passed by the course in September 2015.

However, over the following months I became increasingly concerned about the feasibility of recruiting a sufficient number of participants from this hard-to-reach patient group without having direct access to them on placement. As people with negative symptoms of schizophrenia in the absence of acute positive symptoms will often be discharged back to primary care, I was unsure whether I would be able to identify suitable participants through primary care routes without the funds to remunerate GPs for their assistance. Furthermore, five other trainees in my year had decided to conduct research projects with people with schizophrenia and trainees in the year above had struggled to recruit sufficient numbers of participants for their projects. The tipping point came in the summer of 2016, when I became at risk of losing my access to a car. I realised it would be impossible to recruit and visit a sufficient number of participants for my project without being able to drive. I had to come up with a new project!

As it was late in the day for starting over, I knew that I had to choose a project that could go ahead without the lengthy process of NHS ethics review. I also decided to design the new project as an online study so that recruitment would not be affected by my potential lack of personal mobility.

At the time, I was on my Learning Disabilities placement at Fromeside Secure Services working on a specialist ward for male offenders with autism and/or intellectual disabilities. My placement supervisor, Amy Canning, was extremely generous with her time and ideas to help me develop a clinically relevant project with adults with autism as a study group. From the perspective of forensic risk assessment, Amy was interested in the relationship between paranoia, anger rumination and aggressive behaviour in people with autism. While this idea proved unfeasible to pursue with participants recruited from the community via online methods, in my review of the existing literature on paranoia in autism, I came across recent research proposing a differential phenomenology of paranoia in autism compared to psychosis. In particular, I found two recent papers examining data-gathering style in autism and its possible links to persecutory delusions, which had produced apparently conflicting findings. Both studies had used the Beads Task paradigm, a probabilistic reasoning task that has been well-researched in the context of persecutory delusions in people with psychosis and schizophrenia. I felt that the findings

from the two studies presented an excellent opportunity for me to contribute to 'reproducible science' (Munafò et al., 2017) by replicating aspects of previous research in this paradigm in a novel combination and with a, to date, under-researched client group. I also felt excited that findings from this research might be able to inform the further development and adaptation of CBT interventions for paranoia for people with autism spectrum conditions. When I discovered that the lead author on one of the two conflicting studies was based at the University of Bath and could potentially be wooed as a co-supervisor, I decided to take the leap and design a new main research project.

Gaining ethical approval for the study from the University of Bath ethics committee was straightforward and I was able to benefit from the experience of my fellow trainee, Roz Cooper, who had employed online recruitment methods in her research with people with Autism and generously shared her list of websites and organisations that had helped to advertise her research. Designing online versions of the questionnaires and experimental tasks was time-consuming but enjoyable. Feedback on a draft versions of the full online survey from a pilot participant with autism spectrum condition was invaluable in making the interface and survey flow more accessible to the target group, e.g. by adding visual representations to instructions, annotating some of the questions with explanations as to why they were being asked and revising questions that could be perceived as stigmatising by people with ASC.

The project went live on social media at the start of April 2017, and by mid-May, I had recruited almost twice as many participants as required on the basis of my power calculations – with minimal effort on my part. While there are obvious drawbacks to online recruitment, such as lack of control over the composition of comparison groups, the experience means I will definitely to consider using online research methods in the realisation of future research projects where appropriate.

Future Plans and Directions

I believe that the various challenges I have encountered in realising my research plans have been a helpful learning experience to prepare me for continuing to carry out clinically relevant research within the constraints of a resource-limited NHS environment. I feel passionate about service development and innovation in collaboration with service

users and believe that my systemic training will be a valuable asset in helping me to integrate research evidence and stakeholder priorities in driving processes of organisational change. I have also come to appreciate the importance of writing up case studies as part of clinical work. While this was a much dreaded and painful process at the end of each placement, it was vital to my learning as a therapist, and I feel committed to carrying this practice forward in my future work to ensure that I stay attuned to new theoretical developments and theory-practice links.

References

Bentall, R. P. (2004). *Madness explained*: Psychosis and human nature: Penguin UK.

Dallos, R. (2006). *Attachment Narrative Therapy*: McGraw-Hill Education (UK).

Dallos, R., & Vetere, A. (2012). Systems theory, family attachments and processes of triangulation: Does the concept of triangulation offer a useful bridge? *Journal of Family Therapy*, 34(2), 117-137.

Grant, P. M., & Beck, A. T. (2009). Defeatist beliefs as a mediator of cognitive impairment, negative symptoms, and functioning in schizophrenia. *Schizophrenia Bulletin*, 35(4), 798-806.

Grant, P. M., & Beck, A. T. (2010). Asocial beliefs as predictors of asocial behavior in schizophrenia. *Psychiatry Research*, 177(1), 65-70.

Herman, J. L. (2015). *Trauma and recovery: The aftermath of violence--from domestic abuse to political terror*: Hachette UK.

Kidd, J., & Ziebland, S. (2016). Narratives of experience of mental health and illness on healthtalk. org. *BJPsych Bull*, 40(5), 273-276.

Munafò, M. R., Nosek, B. A., Bishop, D. V., Button, K. S., Chambers, C. D., du Sert, N. P., . . . Ioannidis, J. P. (2017). A manifesto for reproducible science. *Nature Human Behaviour*, 1, 0021.

Van der Kolk, B. (2014). *The body keeps the score*: Viking New York.

Vetere, A., & Dallos, R. (2008). Systemic therapy and attachment narratives. *Journal of Family Therapy*, 30(4), 374-385.

Service Improvement Project

Development of an Online Roadmap of Psychological Support in Collaboration with Mental Health Service Users

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Intended Journal: Journal of Mental Health

This journal has been chosen due to its interdisciplinary and practice-oriented emphasis and its focus on service user involvement.

The unfulfilled promise of e-mental health

E-mental health is an area of growing research interest. The term refers to the use of information and communication technology to support and improve mental healthcare (Riper et al., 2010). The rise of the internet and associated technologies, such as smart phones and apps, have opened up new possibilities for providing information, support and treatment for mental health problems on a wide scale and at a low cost (Leigh & Flatt, 2015). The DoH Information Strategy (May 2012) consequently encourages NHS England services to exploit the potential of digital technologies to improve accessibility and effectiveness of health services and to increase health literacy and self-management amongst patients.

But what is the potential of e-mental health for the delivery of psychological support? Provision of psycho-education and self-help resources via the internet has been found to be cost-effective, convenient and likely to reach more diverse social groups than face-to-face provision (Barak & Grohol, 2011). The evidence base for the clinical effectiveness of internet-based psychological self-help resources, such as c-CBT, administered within the context of clinical trials (Barak, Hen, Boniel-Nissim, & Shapira, 2008; Christensen, Griffiths, & Farrer, 2009; van Spijker, van Straten, & Kerkhof, 2014) has been steadily growing. A recent meta-analysis of web-based psychological interventions found them to be as effective as face-to-face therapies (Barak et al., 2008).

However, there is a relative dearth of research into service users' views and preferences with regard to using e-mental health (Riper et al., 2010). Attrition from internet-based interventions is known to be high, and while this may be regarded as a natural feature of the medium (Eysenbach, 2005), little is known about predictors and service user reasons for drop-out or lack of engagement (Nicholas et al., 2010). Limited evidence from small scale studies suggests that concerns over privacy or general dislike of digital technologies may deter some service users from accessing self-help resources online (Proudfoot et al., 2010). In addition, amongst adolescents, intention to seek help for mental health problems online is associated with higher levels of health literacy and thus unlikely to be increased by provision of internet-based resources alone (Bradford & Rickwood, 2014).

Blaschke and colleagues (2009) identify attitudinal factors (e.g., doubts about benefit and/or low confidence in handling computers) and factors relating to training and support as two of the five barriers to accessing online resources specifically for older people. However, lack of confidence/competence in identifying trustworthy resources are likely barriers across all age groups.

Qualitative studies with a range of patient groups with different psychological problems found that service users may feel unsure about what to expect from online self-help and may doubt whether generic materials can be helpful to personal problems (Murray et al., 2003). They may also be unaware of the range of problems for which resources are available and may lack the confidence and motivation to go online to identify resources that would meet their needs (Aref-Adib et al., 2016). Especially during periods of acute distress and low mood and motivation, it can be challenging for those unfamiliar with using e-mental health to learn new behaviours. An increasing range of good quality resources are freely available on the internet, but it can be difficult for service users to find relevant material without signposting (Morahan-Martin & Anderson, 2000).

In summary, there remains a gap between the growing number of evidence-based psychological interventions currently available on the internet that have been found to be effective in the context of controlled studies, and the uptake of these resources by those experiencing the mental health problems they have been designed to address.

The promise of service user involvement in mental health services and the potential to bridge the gap

UK health and social care policies have embraced the vision of patients as active partners in their care as a vital requirement for creating an economically sustainable healthcare system. Public health promotion aims to create fully engaged patients who make appropriate use of services and feel sufficiently informed and empowered to practise effective self-management of long-term conditions (Coulter, 2006). As part of the NHS modernisation agenda in the late 1990s, the National Service Framework for Mental Health (1999) promoted service user involvement as a strategy to ensure service design and delivery were responsive to patient needs. The 2001 Health and Social Care Act (DoH,

2001) created a statutory obligation for all NHS organisations to involve service users in the planning and evaluation of services to achieve genuinely patient-centred service provision. While a systematic review of patient involvement studies (Crawford et al., 2002) failed to find evidence that service user involvement improves quality of healthcare or patient satisfaction, it also acknowledged the difficulty of demonstrating such effects. However, the review did find evidence that service user involvement can make a difference to how services are provided.

Kirby (2004) identifies three different levels of service user involvement: *consultation*, *collaboration* and *user-controlled* research. Whereas *consultation* typically seeks service users' views as a one-off activity to inform organisational decision-making without necessarily adopting the suggestions made, *collaboration* involves active, on-going partnership with service users in the development of services. In *user-controlled* research, initiative for projects and powers of decision-making reside with service users, whilst service professionals and academic researchers act merely in a consultative capacity. Especially at the level of *consultation*, there is a risk that service user involvement will be perceived as tokenistic. Particularly in the field of mental health, the emancipatory interests of the mental health survivor movement have, at times, shown themselves to be irreconcilable with governmental policy agendas (Tait & Lester, 2005). Indeed, some critics have argued that the NHS agenda of seeking to involve service users as partners is a way of silencing and taking the wind out of the sails of the more radical and critical voices of the survivor movement (Noorani, 2013). Despite these tensions, organisations such as *INVOLVE* and *SHAPING OUR LIVES* have been set up with DoH funding to actively promote service user involvement in research and have developed criteria to ensure that service user involvement is an empowering rather than exploitative process (Beresford, 2005; Telford, Boote, & Cooper, 2004).

Describing the benefits of service user involvement specifically in mental health, Tait and Lester (2005) argue that service user involvement can help to increase the understanding of mental distress, promote alternative approaches to understanding mental illness, can bring about greater social inclusion and can in itself have therapeutic

effects. Noorani (2013) employs the concept of 'experiential authority' to capture how self-help and support groups can become vehicles for mental health service users as 'experts-by-experience' to exercise political power and challenge the disempowering effects of a reductionist medical model of mental illness. The creation of platforms in the real and virtual world for mental health service users to share their experiences can help to erode the stigma around mental health. Furthermore, experienced mental health service users can act as therapeutic 'coping models' (Meichenbaum, 1971) to those who encounter formal mental health services for the first time. A systematic review of peer support workers within mental health services (Repper & Carter, 2011) concluded that peer support can improve self-esteem and a sense of self-efficacy amongst service users, convey hope in the possibility of recovery and promote greater self-management of mental health difficulties as well as help service users to increase their social networks.

The 'Online Roadmap of Psychological Support' Service Improvement Project

This paper reports on a Service Improvement Project (SIP) undertaken in a large community mental health service.

In thinking about how service users' experiences of psychological support could be utilised to empower other service users with the confidence and skills to access online resources, a psychologically informed conceptual starting point was provided by the *HealthTalk* model (http://www.healthtalk.org). *HealthTalk* presents peer testimony in the form of video- and audio-clips of excerpts from rigorous research interviews with patients on a broad range of physical and mental health conditions (Kidd & Ziebland, 2016). Interview excerpts are contextualised with summaries that integrate the voices of lived experience with medical information and links to further resources and support. Vygotsky's (1987) notion of the *Zone of Proximal Development* (ZPD) describes the difference between what individuals can achieve by themselves, and what they can master when assisted by a more competent peer or teacher. Following Vygotsky, Bruner and colleagues (1976) coined the term 'scaffolding' to describe how a supportive structure – mediated verbally or non-verbally by a shared social practice - can facilitate the performance of a task that otherwise would have been beyond the novice's reach. Drawing on the ZPD as a model for peer learning and modelling of behaviour change

(Chaiklin, 2003; Lave & Wenger, 1991), service users' experiential accounts of using psychological therapy and other forms of psychological support can provide scaffolding and encouragement to novice mental health service users to access psychological resources for themselves. Placing experiential accounts of service user peers at the centre of a facilitative gateway to online resources might thus 'bridge the gap' between the potential of e-mental health and the barriers to its more wide-spread uptake by mental health service users. This project sought to consider this approach within the service.

Service Context

The community mental health service within which the project was conducted had recently been recommissioned, resulting in a new partnership between NHS services and third sector health and social care agencies. The recommissioning brief required the new leadership to commit to co-production with service users in all aspects of service development. To facilitate this, a number of service user groups, called 'reference groups', were set up to collaborate with service staff on different work streams, including a group attached to the psychological therapies service which met monthly to advise on developments relating to the provision of psychological support.

At the same time, the organisation prioritised a major redesign of the service website, which until then had featured minimal and primarily static content. Staff in the psychological therapies service were keen to use this opportunity to expand the team's online representation in ways that would reflect their multiple roles and skills and that could provide information to community mental health practitioners (henceforth referred to as recovery staff) and service users alike about the range of psychological services and support options available within the service.

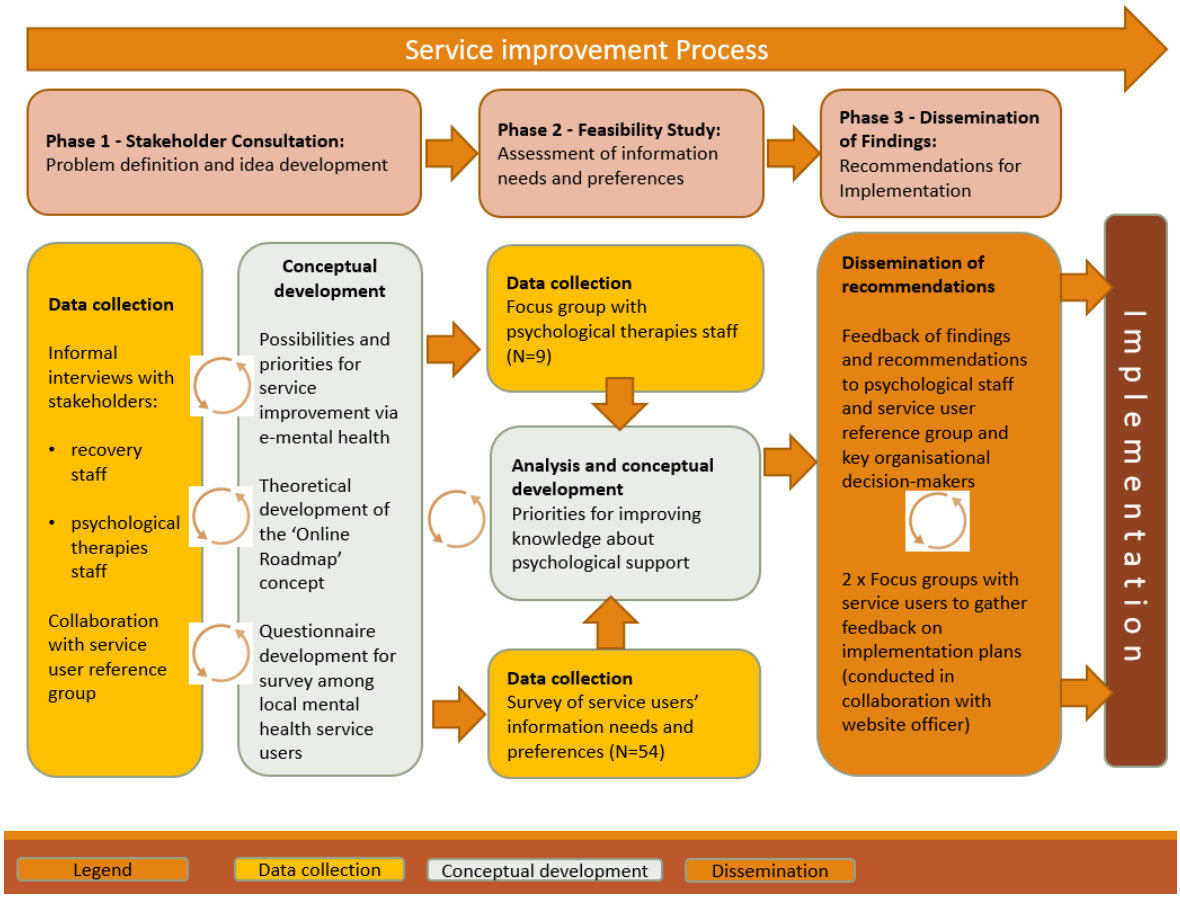

Figure 1: Phases in the Iterative Service Improvement Process

The SIP contributed to these ongoing developments through iterative cycles of problem definition, idea generation, data-gathering and analysis, feedback of findings, prioritising and further planning. This was done in consultation and collaboration with service users and staff, and proceeded in three phases (see Figure 1):

(1) stakeholder consultation

(2) feasibility study

(3) dissemination of key findings and recommendations for implementation.

Aims and methods for each phase and results taken forward into the next phase are described below.

Phase 1: Stakeholder consultation

Aims

The aims were:

- To identify key concerns and possible targets for service improvement under the broad heading of improving information about psychological support within the service amongst psychological therapies staff, recovery staff and service users.
- To stimulate discussion about how e-mental health might help to improve knowledge of and access to psychological support without the need for additional staff resources.
- To invite feedback about the concept of an interactive internet gateway structured around service user experiential accounts to bridge the gap between existing online psychological resources and uptake of these by local service users.
- To develop a way to assess the feasibility and acceptability of the concept with local service users.

Methods

Informal interviews were held with psychological therapies staff, recovery team staff and the service user reference group to explore their perceptions about current problems with regard to knowledge of and access to psychological information and interventions within the service. Identified areas for improvement (Table 1) were discussed further at the psychological therapies team meeting and the service user reference group.

Findings

Table 1: Potential Areas for Service Improvement Identified by Stakeholders

Psychological Therapies Staff	Recovery Staff	Service User Reference Group
A limited understanding within the Recovery Team about the range of therapies that are available'	*Lack of transparency about eligibility criteria for accessing therapy - uncertainty as to who to refer*	*Lack of transparency about eligibility criteria and waiting times for individual therapies*
Clarify that a large amount of psychological work takes place indirectly, e.g. via team formulation and clinical supervision of recovery staff	[Misconceptions about the range of mental health presentations that can or can't benefit from psychological support]	**Perception of individual therapy as the 'gold standard' of psychological support, lack of awareness about other options such as groups, self-help or indirect work via recovery staff**
Referrals can be opportunistic and based service user pressures or complexity rather than potential for treatment benefit	[Misconceptions about what specific types of intervention entail, who they will suit and how long they will take]	*Lack of knowledge about how to access psychological support within the service*
Service users request specific interventions that are not available within the NHS or that are not evidence-based for the presenting problem	Uncertainty as to how best to prepare service users for therapy, support those who are in therapy and assist in maintaining benefits from therapy	**Lack of knowledge about the range of support available within the service, their respective evidence base and why some interventions are not being offered**
Clarify the level of commitment and environmental stability required to gain maximum benefit from psychological work	**Simplistic equating of specific diagnoses with specific interventions (e.g. "a person with BPD always needs DBT")**	**Misconceptions about specific types of therapies – not knowing what to expect or fixed views on which therapy is desired**
Create realistic expectations about the nature of different psychological interventions amongst service users		**Better information about how different types of therapies differ from each other and how to make informed choices between them**
Clarify how different levels of psychological support fit with service users' recovery journey: when is the right time?		Lack of understanding of how different providers of psychological support work together – experience of being sent from pillar to post
Limited use of /signposting to psycho-education and self-help resources freely available on the internet	**Lack of awareness of high quality psycho-education and self-help resources freely available on the internet**	**Lack of confidence to identify reliable sources of information on the internet**
		Concerns over privacy when accessing the internet and in particular, online discussion groups

[1] Issues relating to psychological referral were not taken forward as improvement of the referral process had been identified as the target of a parallel SIP (Fiddick et al., in preparation).

The key concerns emerging from consultation with stakeholders centred around the need for greater clarity about forms of therapy available within the service and what they might involve, how to refer, increased understanding about necessary preconditions for psychological therapy and awareness about alternatives involving indirect work, as well as guidance on what service users and recovery staff could do to maximise gains from psychological intervention before, during and after therapy. Alongside these themes, discussions also suggested a relative lack of awareness of and or/confidence in accessing online resources amongst psychological therapies staff, recovery staff and service users alike.

A decision was made to target information about psychological support directly at service users rather than indirectly via recovery staff and therefore, to link in with the redesign of the public website rather than the organisation's internal webpages. This meant that potential website contents would have a broader reach, being accessible to both the public and those within service, but it also meant that the inclusion of experiential accounts and other forms of personally identifiable information needed to be considered with special care.

To explore the acceptability and feasibility of ideas and priorities for improvement beyond the reach of the service user reference group, it was decided to conduct a city - wide survey amongst local service users. A brief pen-and-paper survey questionnaire was collaboratively designed and piloted over a series of meetings with the reference group (Appendix 3). The group also advised on methods to maximise participation in the survey. The concept of a facilitative gateway based on a peer social learning paradigm received a positive response from all stakeholder groups and was renamed as the 'Online Roadmap of Psychological Support' (ORPS).

Phase 2: Feasibility study

Aims

The aims for Phase 2 were:

- to assess service users' current levels of knowledge about locally available therapies and other forms of psychological support.

- to establish service users' current use of online resources and preferences for accessing psychological information and support.
- to elicit service user and psychological therapies staff priorities and suggestions for ORPS contents and hyperlinks.
- to assess the feasibility of the ORPS in terms of internet access and gathering experiential accounts of using psychological support from local service users.

Methods

Ethical approval to conduct the research and development activities associated with the SIP was granted by the University Ethics Committee and the Trust's Service Improvement Manager (Refs: 15-226; E2015.014; Appendix 2).

Service user questionnaire survey. The survey was fronted by a letter of invitation providing a brief description of the SIP and the ORPS concept in the context of service recommissioning and website redesign (see Appendix 3). It employed a multiple-choice format with space for comments to volunteer additional information. Questions asked about current modes and preferences for accessing the internet and about service users' experience and information needs regarding different types and formats of psychological support.

To maximise uptake of the questionnaires by a broad range of service users, the reference group had recommended that CMHT staff should personally invite the service users on their caseload to take part by handing out copies of the survey with freepost reply envelopes attached whenever they met with service users. However, when the researcher approached CMHT teams for help with distributing the survey, it quickly became clear that the majority of staff felt unable to take on this role due to workload pressures. It was therefore decided to employ self-selection sampling instead. Boxes with questionnaires and envelopes were deposited in the reception areas of the four service sites across the city and posters were put up in waiting areas and toilets, inviting participants to complete questionnaires whilst waiting for their appointments. Participation was incentivised with

the opportunity to enter a prize draw for a £50 shopping voucher at the suggestion of the reference group. Participation was anonymous, but the final section invited respondents to provide contact details if they were willing to consider taking part in an interview about their personal experiences of psychological support. The survey was advertised with posters in the reception areas of four service sites. Copies of the postal survey with freepost reply envelopes attached were laid out next to posters. Receptionists, CMHT and psychology staff were encouraged to alert service users about the questionnaire. The survey ran from December 2015 to March 2016.

Focus group with psychological therapies staff. A 45-minute focus group was held with members of the psychological therapies service (N=9) to discuss their views on the proposed ORPS structure and contents and identify possible concerns and barriers to its realisation. The focus group was audio-recorded and themes identified using Nvivo QSR qualitative analysis software.

Findings from Service User Questionnaire Survey

54 service users completed the questionnaire, representing around 2-3% of the total population. Due to reliance on self-selection sampling, it was not possible to establish exact response rates, but number of surveys returned from each site sites varied between 9 and 21 and together accounted for 27% of the total of 200 questionnaire copies that had been distributed. Table 2 provides respondents' demographic data. The mean age of respondents was 42.2 years (range 18-76, SD 14.8). Compared to the psychological therapies caseload for 2016, the survey sample included a greater proportion of older and male respondents (caseload 70% female and only 9% aged over 65).

Table 2: Demographics data for of service users completing the survey (N=54)

	number	percent
Gender		
Male	20	37.3
Female	30	55.5
missing	4	7.4
Ethnicity		
White	45	83.3
Mixed	2	3.7
Asian	1	1.8
missing	6	11.1
Religion		
None	30	55.5
Christian	9	16.6
Jewish	3	5.5
Other	3	5.5
Missing	9	16.6
Sexual identity		
heterosexual	31	57.4
homosexual	5	9.6
other	2	3.7
prefer not to say	9	16.6
missing	7	13

Over three quarters of respondents (77.7%) had had previous experience of face-to-face therapy (individual and/or group). While these experiences included therapies in IAPT services, third sector organisations and private therapies, it is worth noting that amongst the local service user population, in the year 2016, only around 15% of mental health service users were on the psychological therapies caseload, so the survey sample is likely to have been more psychologically interested and informed than the local service user population as a whole, reflecting a potential bias arising from self-selected recruitment.

With regard to internet access (Figure 2), 5.5% of respondents stated that they did not currently have access to the internet. Of those with internet access, the majority used private modes of access via home Wi-Fi, phones and tablets. 20% said they accessed the internet in public places such as libraries, but only 5.5% did so without having private access as well.

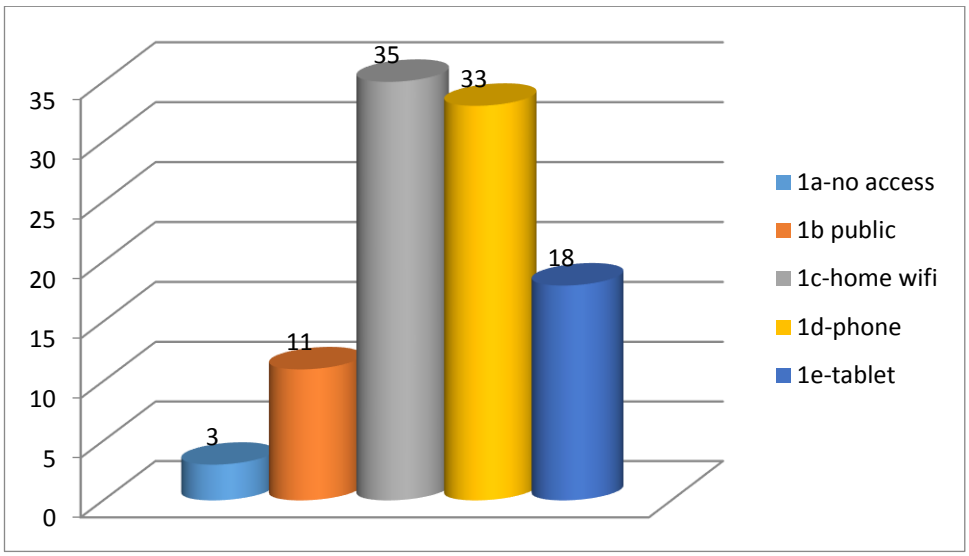

Figure 2: How Do Respondents Currently Access the Internet?

A significant minority of service users (27.5%) said that they did not want to use the internet to access information and support for mental health, and 86% of these said so despite having private access. People who did not want to access support online were of comparable age to those who did (mean age 45.5, range 25-60). The survey did not explore reasons for not wanting to use the internet in this way, but one respondent provided the following comment in the free-text section:

> *"I'm paranoid about the internet and worried about being bullied or being accused of bullying in chat rooms. I would possibly use it if I had to log in, but not open access. Then I would only view statements. I am worried about the reliability of online resources."*

Another service user explained their preference as follows:

> *"I suffer from migraines and sitting for a long time viewing items online can bring on a migraine. I also struggle with concentration, so prefer to print things and read at my leisure. However, I feel this will be a really useful tool."*

The majority of service users (61.8%) said they were already using the internet to access mental health information, but almost half of this group (29.4% of the total) said they would like help with finding trustworthy information. Another 11.8% of respondents

said they did not currently use the internet for this purpose because they did not know how to find relevant contents.

Overall, these findings suggest that provision of psychological support online is a feasible option for the majority of service users, but that such provision needs to be scaffolded and signposted to facilitate optimal uptake of resources. Findings also indicate that there is a substantial minority of service users for who e-mental health is not an acceptable medium, clarifying the importance for services to offer resources in a range of modalities, if they do not want to risk excluding certain populations.

Service users were asked to rate their knowledge about different types of psychological interventions available within the service, and to indicate which kinds of therapies they would like to know more about. CBT and mindfulness emerged as the two types of interventions that respondents felt most knowledgeable about, possibly reflecting the fact that for many service users the route into secondary mental health services is via IAPT services, which specialise in providing these interventions.

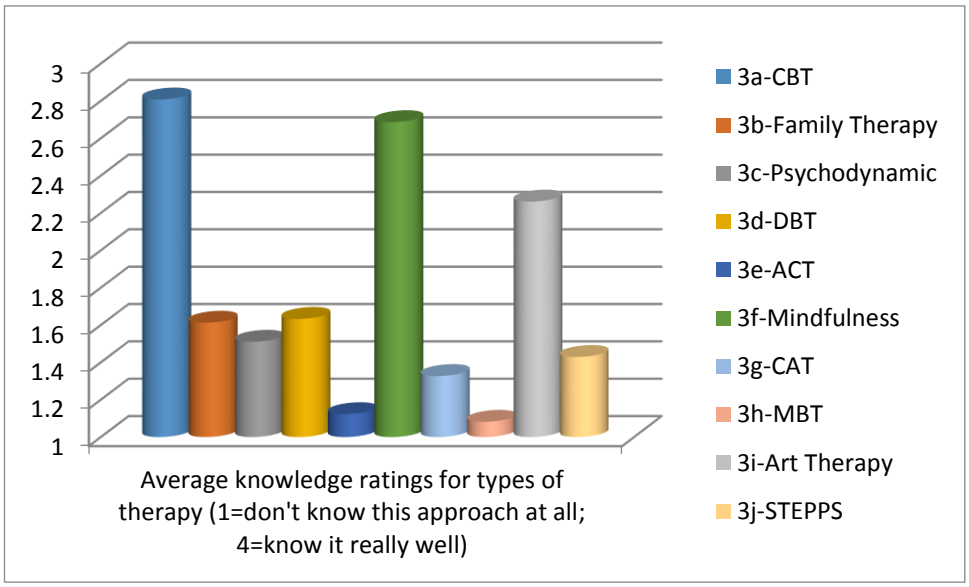

Figure 3: Respondents' Knowledge Ratings of Types of Therapy

All other interventions, with the exception of art therapy, had mean scores of below 2 ("I know a little bit). Respondents felt least knowledgeable about Mentalisation-Based Therapy (MBT) and Acceptance and Commitment Therapy (ACT). These two interventions were also among the top four choices (receiving more than >10 votes each)

of therapies respondents wanted to know more about, alongside DBT and STEPPS. CBT and Family Therapy received the least amount of votes, with four votes each.

In terms of respondents' information needs regarding different formats of psychological support, preferences for additional information largely reflected respondents' previous experiences (see Table X and Figure X below). For example, one-to-one therapy received the highest number of votes (34) for wanting additional information, even though 75.9 % of the sample had had previous experience of this format. Information about online self-help media (such as cCBT) and online chat received less than 10 votes each, and only 20% and 11% of respondents, respectively, had experience of using these formats. Only one in four respondents had experience of using websites or peer support groups, and one in five had experience of using self-help media other than books, such as mood apps. An exception to this trend was a preference to learn more about websites for specific mental health problems, which ranked second (21 votes) to individual therapy as a support format that respondents wanted to know more about. 14.8% of respondents stated that they knew all they wanted to know about the different formats for psychological support.

Table 3: Percentage of Respondents with Experience of Types of Psychological Support

Type of Psychological Support	Percent
6a-one-to-one therapy	75.9
6b-group-based	40.7
6f-selfhelp books	35.2
6g-selfhelp worksheets	27.8
6c-peer support	25.9
6e-specific websites	25.9
6h-self-help media	20.4
6d-online chat	11.1

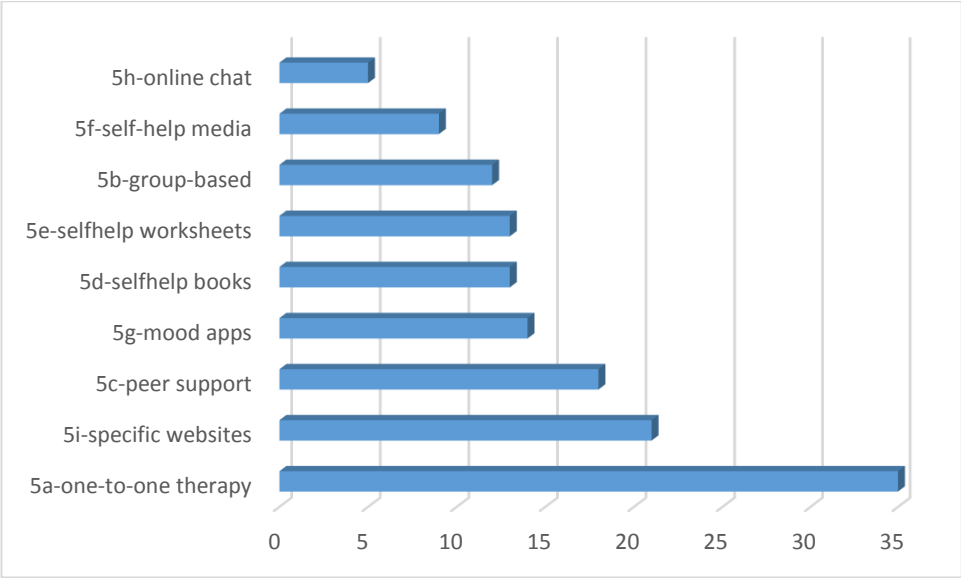

Figure 4: Formats of Psychological Support Respondents Want to Know More About

Overall, these findings are encouraging and suggest that while a minority of local service users do not have information needs in this area and are currently accessing online psychological support in a range of formats, there is potential for the uptake of online resources to be substantially increased and there is significant interest amongst the majority of service users to learn more about the e-mental health options available to them.

To establish priorities for contents with which to populate the ORPS, respondents were asked to indicate the kinds of psychological difficulties for which they wanted further information and support. They could select as many areas of difficulty as they wanted and could also provide additional suggestions. Figure 5 shows the difficulties respondents' prioritised in descending order: *Help with managing worry/anxiety* and *low mood* received the most votes, followed by *managing strong emotions*, *sleep problems*, *social anxiety* and *intrusive thoughts*.

Finally, the idea of conducting qualitative interviews with service users to produce peer testimony that could be used to scaffold access to online resources appeared highly feasible, with 27.7% of respondents indicating a willingness to be approached for an interview about their personal experiences of psychological support.

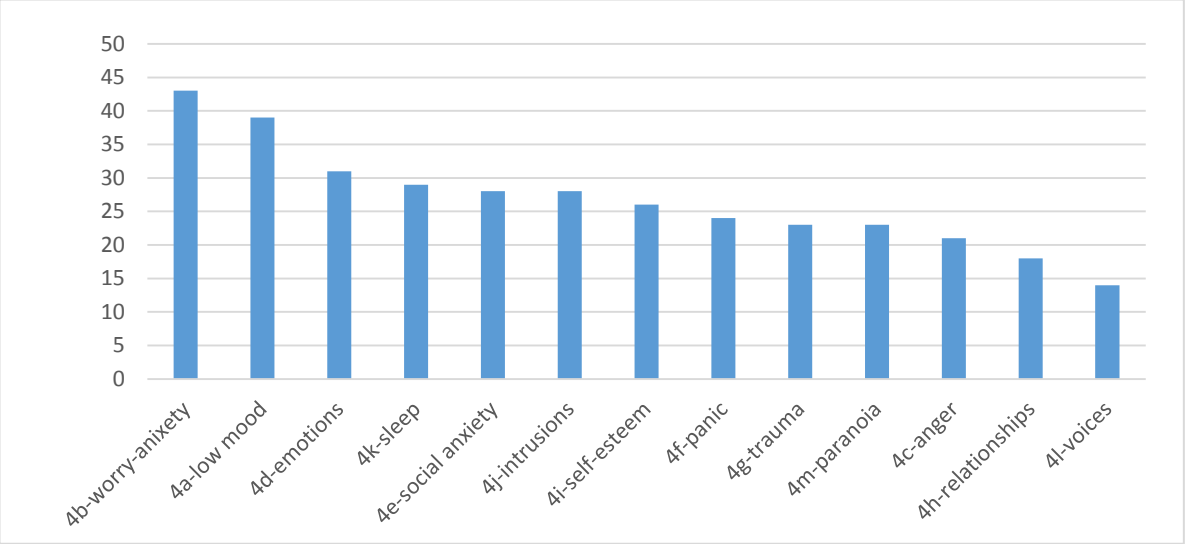

Figure 5: Information and support needs for psychological difficulties in order of priority

Findings from Focus Group with Psychological Therapies Staff

Nine psychological therapies staff participants took part in a 45 minute focus group. This included 6 clinical psychologists, two art therapist and one administrator and represented 22.5% of all staff. Table 4 summarises the key points emerging from focus group discussion.

Participants expressed hopes that the ORPS could help to create more realistic expectations among service users about how therapy can be helpful and the requirements and preconditions service users might need to meet for particular types of therapies. Previous research suggests that such information can improve therapy engagement and attendance rates (Constantino, Ametrano, & Greenberg, 2012; Greenberg, Constantino, & Bruce, 2006). Participants were also keen for the ORPS to educate service users about why certain types of therapy might not be provided within the Trust and the factors that need to be considered in the timing of therapy and other forms of psychological support, provided indirectly or via self-help, during the course of recovery (e.g. stabilisation work required before addressing traumatic memories). Participants felt the ORPS should include video clips of interviews with service staff as well as service users to address these issues.

Table 4: Key Points from Psychological Therapies Staff Focus Group (N=9)

Suggestions for ORPS Structure and Contents
• Design and structure of ORPS to reflect the recovery journey of service users through the service and how psychology features within this
• Concern that increased info about available therapies will drive up demand when current provision is already stretched - need to emphasise role of psycho-education and self-help resources in preparing for therapy or offering alternatives to therapy
• Clarify that face-to-face therapy requires the ability and motivation to commit to working collaboratively and actively, more than just being listened to by an expert
• Need to be transparent about why we do not offer certain therapies - educate about evidence base and NICE guidelines; sometimes no staff available with training in the specific areas
• Clarify how psychologists and psychotherapists work indirectly through supervising and consulting with recovery staff: psychological work does not necessarily require direct contact with psychologist
• Embody a formulation-based understanding of mental health problems, non-medical, normalizing, destigmatizing => Organisation along areas of difficulty, not diagnosis
• Videos of therapists explaining therapies and service users describing experiences of therapies: helping to debunk myths, creating realistic expectations and alleviate fears, e.g. about joining therapy groups
• A genuinely psychologically informed structure - away from the medical model. Idea to organise information according to areas of difficulty (i.e. sleep, emotion regulation, anxiety, etcetera) rather than diagnostic categories.

In terms of structure, participants suggested an organisation around trans-diagnostic symptoms and mental health difficulties (e.g. mood regulation, rumination, dissociation) as a psychologically-informed alternative to a structure of contents organised on the basis of psychiatric diagnostic groupings.

Phase 3: Feedback of Findings and Recommendations

Aims

Aims for Phase 3 were:

- To share findings from Phase 1 and 2 with service users and discuss ideas for implementation and evaluation.

- To share recommendations for structure and contents of the ORPS with key decision-makers within the service to guide implementation within the context of the redesign of the wider service website.

Methods

A summary of findings from Phase 2 was presented and discussed at a service user reference group meeting and the city-wide psychological therapies team meeting.

Between September 2015 and July 2016, a series of meetings was held with members of the system leadership team, including consecutive website and communications officer. Meetings included interim discussion of findings and adaptation of original ideas for the ORPS in view of service constraints. A draft version of recommendations was presented and discussed in two focus groups with service users held in June 2016.

SIP Recommendations and Implementation

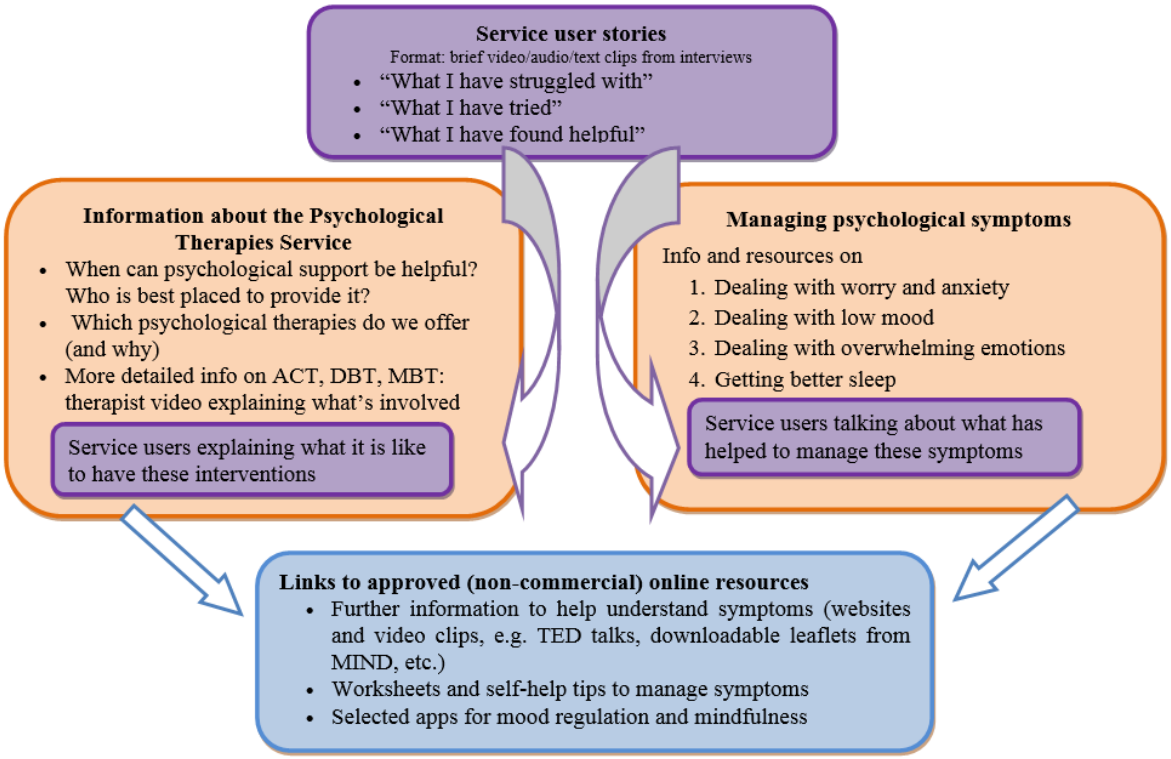

Figure 6: Recommendations for Structure and Initial Content Priorities of the ORPS

Final recommendations for the ORPS were shared with the system leadership team in the form of bullet points for priority contents to produce and a list of external hyperlinks based on stakeholder preferences and suggestions. Figure 6 provides an at-a-glance summary of these recommendations. Table 7 details how specific recommendations have been implemented as part of the service website redesign since June 2016. An impact statement from the website officer can be found in Appendix 7. Appendix 8 provides screenshots of the redesigned website to illustrate how the ORPS concept has been implemented structurally.

The redesigned website features information about psychological services and support options available within the service and the wider local community, as well as links to external psychological resources (self-help tools, mood apps, and national websites and support groups). Written information is complemented by video narratives by psychological therapies staff to clarify the scope and breadth of psychological work. It was not possible to produce audio-visual recordings of service user peer testimony within the time- and resource frame of the SIP as had originally been planned. However, already existing peer testimony and written case studies featuring first-person narratives by local services are continually being added to the website contents.

Table 7: SIP Recommendations and Implementation

Recommendations	Implementation (refer to Appendix 9 for illustrative screenshots of the website)
Recommendations for information about psychological support available within the local mental health service	
Written information about the direct and indirect work of psychological therapies in the form of FAQs, covering the following:	Implemented via provision of written information and hyperlinks to YouTube video clips
• What's the difference between psychiatrists, psychologists and psychotherapists? (formulation-based, not dealing with medication, range of approaches, but no couch)	Psychological Therapies Homepage titled 'Who we are' with service user quotes and some explanation of types of work the team are involved in.
• What are the different ways in which the psychological therapies service supports service users' recovery? (describe direct and indirect work)	5 minute YouTube video with a member of psychological therapies staff talking to these issues in response to FAQ-style headlines
• What kinds of psychological therapies are currently being offered in the service?	4 minute YouTube video with a member of psychological therapies staff talking to these issues in response to FAQ-style headlines
• Why does BMH offer only certain types of psychological intervention? (reference to NICE guidelines with links, evidence-base and its limitations, skills set of local therapists)	Not implemented
Fact sheets describing the different types of currently therapies and what they involve, with priority for ACT, MBT, DBT and STEPPS	Short information leaflets for each of the available therapies that can be downloaded and printed as pdfs are currently being revised and updated.
Recommendations for external e-mental health resources	
Links to carefully selected non-commercial and NHS-approved apps and self-help resources to address trans-diagnostic symptoms of mental health difficulties (linked to peer service user testimony of using these)	The 'useful links' section of the website has subheadings for links to mood and mindfulness apps and self-help guides, as well as podcasts and TED talks, including short descriptions of each.
Links to external organisations and support groups	The 'useful links' section has a subsection 'Information about mental health support groups featuring links to national and local support groups.

Recommendations for creation of audio- and video clips of peer service users' experiential accounts of using psychological support	
Preparation of Interview Schedules, Participant Information Sheets and Consent Forms to enable collection and copyrighting of such data	Not taken up
e.g. Experience of doing a STEPPS group e.g. Experience of having ACT: what it involved and how it has helped Integrated with factual information and hyperlinks to external online resources	In its 'Service User and Carer' section, under the heading ''getting involved' the website features a number of case studies written as first person experiences, with embedded hyperlinks to psychological support options that are being described. A film made within the Trust as part of a previous SIP by a Bath University Trainee (Andrew Merwood) about expectations and experiences of having therapy will be made available via hyperlink.
Recommendations for Publicising the ORPS	
Via service user newsletters	Monthly newsletters are sent to registered service users via hardcopy or email and alert them to new website contents
Referenced as a helpful resource as part of the welcome letter that new service users receive from the community mental health team	Not implemented
Recommendations for evaluating the ORPS	
Logging of number of visitors /traffic for the ORPS-related elements of website to establish uptake of the different elements	Currently, only data for traffic on the mental health service website as a whole is available
Facebook style 'Like' buttons next to specific contents such as videos and apps	Currently only available for external YouTube-based contents
Option to leave free-text comments next to specific contents	Thought to be too maintenance and resource-heavy
A brief pop-up questionnaire on navigating away from the website	May be implemented according to system leadership priorities for evaluation

Discussion

This report describes a successful example of carrying out service improvement activities in collaboration with mental health service users. The aims and methods of the SIP were developed iteratively in consultation with stakeholders and remained fluid and

responsive to service user suggestions and mental health service priorities and constraints throughout its course.

However, not all of the original ambitions of the project could be fully realised and limitations of findings need to be considered.

With regard to the aims of Phase 1, the SIP successfully managed to stimulate discussion amongst staff and service users about the potential of e-mental health to increase access to psychological information and self-help. It was able to identify hopes and concerns regarding improved knowledge amonst service users and CMHT staff about types and availability of psychological support and increased use of online resources in direct and indirect psychological work. Phase 1 clarified priorities for service improvement and helped to refine the focus and methods for Phase 2.

Phase 2 aimed to assess service users' information needs and preferences with regard to psychological support, to establish their current rates of accessing online resources and to examine the acceptability of the ORPS concept, and in particular, feasibility of collecting peer testimony about personal experiences of psychological support in an audio-visual format.

The questionnaire survey was completed by 2-3% of the total population of mental health service users and included a reasonably diverse sample of participants. The use of self-selection sampling meant that it was not possible to assess exact response rates or to compare differences between responders and non-responders. Strategies to reduce response bias included incentivisation with a shopping voucher prize draw and the option to complete questionnaires anonymously. Nevertheless, self-selection bias in the form of a 'volunteer effect' is likely to have arisen, as individuals with an active interest in the topic under investigation are more likely to take part in research (Eysenbach & Wyatt, 2002). Presence of such a self-selection bias amongst the survey sample is evident with regard to the large proportion of participants with previous experience of psychological therapies (78%) and the fact that 41% of participants followed the invitation to make additional comments to share their, often quite negative, experiences of accessing psychological support within the service.

Findings from the survey provided useful information on information needs and preferences with regard to different types and theoretical models of psychological

support and also helped to establish priorities for improvement of information provision around specific transdiagnostic difficulties. However, due to the self-selection bias, it can be assumed that survey participants were more psychologically informed and therefore the high knowledge ratings for cognitive behaviour therapy, mindfulness and psychodynamic therapy should not be taken as representative for the service user population as a whole. It is also important to note that a significant minority of service users (27.5%) indicated that they did not wish to use the internet to access psychological information and support. It is important to ensure equity of access to relevant information and support for this group.

Survey responses demonstrated the feasibility of collecting peer testimony about using psychological support in terms of service users' willingness to share their personal experiences. However, organisation constraints in terms of lack of financial and staff resources and governance restrictions meant that the production of audio-visual peer testimony was not feasible within the time frame of the SIP.

Phase 3 aimed to share findings and recommendations for contents and structure of the ORPS with stakeholders and key decision-makers to guide implementation. This report describes a successful example of carrying out service improvement activities in collaboration with mental health service users. The aims and methods of the SIP were developed iteratively in consultation with stakeholders and remained fluid and responsive to service user suggestions and mental health service priorities and constraints throughout its course. The availability of resources for the parallel redesign of the wider service website and the creation of a dedicated Communications Officer post within the service made it possible for many of the recommendations for the ORPS to be successfully implemented within a relatively short space of time. However, it also meant that the ORPS concept, originally designed as a coherent structure, had to be broken up into separate headings and webpages to fit in with the overarching structure and style of the service website (see Appendix 9). This meant that the scaffolding element of peer service user testimony as an Ariadne's Thread to guide novice website users' access to online resources could not be fully realised and may thus have been reduced in its potential to bridge the gap between e-mental health and update by its target groups.

Limitations of the SIP

Service improvement efforts should ideally include evaluation to demonstration that the service has indeed been improved. The ORPS aimed to increase service users' knowledge of psychological support available within the service and promote their uptake of online resources. Unfortunately, it was not possible within the time and resource-frame of the project to repeat the service user survey to gauge the impact of the ORPS. While recommendations included ideas for evaluation of online contents such as Like buttons, comment boxes and pop-up questionnaires, changes in staff and service priorities meant that these could not be realised within the time-frame of the project. Similarly, it was not possible to obtain data on website traffic for the specific subsections of the service website featuring the ORPS elements.

Constraints on the Implementation of Recommendations

Originally, the lead researcher had envisaged producing at least some of peer service user testimony as a prototype and had created consent documents and obtained ethical approval to gather such material (Appendix 5). However, alongside lack of resources, organisational constraints on recording and storage of audio-visual material meant that this aspect of the project could not be realised. While there was strong initial enthusiasm and dedication of resources to co-production in service redesign directly after recommissioning, excitement and funds gradually waned and some positions had to be cut, which constrained the full implementation of SIP recommendations. For example, there were concerns among the organisational decision-makers over who would be responsible for keeping online materials up to date and for responding to service user requests to remove or alter their contents. More interactive forms of service user involvement in using the website (e.g. ability to comment on contents or add resource links) were also seen as potentially risky, in terms of the service having overall responsibility for website contents and insufficient resources to provide continuous monitoring and management of such 'live' contents.

Thus, while during Phase 1, the ORPS concept and the survey to assess its feasibility study achieved service user involvement at the level of *collaboration*, during Phase 2 and 3 involvement remained primarily at the level of *consultation* (Kirby, 2004).

The ORPS was developed with the intention to empower mental health service users, but its potential to do so was to some extent compromised by the way in which service priorities were imposed during its implementation, i.e. the need to conform to the structures of the wider website, which has multiple functions and audiences besides informing service users. Service users have the opportunity to feed back to the communications officer about their experiences of the website and newsletters regularly invite them to do so – however, control and development of, as well as responsibility for contents, remains firmly with the service.

Challenges for Achieving Service User Empowerment within the Structures of Statutory Mental Health Services

A recent UK survey of service user involvement in mental health research (Patterson, Trite, & Weaver, 2014) found that a majority of respondents reported positive experiences of their involvement in research and service improvement: involvement could provide a sense of purpose, reduced self-stigma, enhance confidence and self-respect and encourage the development of self-management strategies that promote mental well-being. However, only 50% said they felt that academic researchers valued their active participation and 70% felt marginalised in mental health research (2014:72).

Providing service users with all the information they need to make informed decisions and substantial contributions to service development is time-consuming for researchers and service users alike. Many service users contribute to service improvement without financial remuneration. While the reference group members in this project got paid for their time and travel expenses as part of the service commitment to co-production, for survey respondents, resources only permitted for a prize draw incentive instead of individual reimbursement. However, some scholars have argued that remuneration of service users as quasi-employees of the service may curtail their ability to speak out on broader socio-political issues in the provision of mental healthcare beyond specific aspects of service delivery in isolation. Noorani (2013) describes how the survivor movement has gradually been transformed into service user roles and thereby become vulnerable to having its political power limited by service-imposed constraints on what that role can involve. He proposes that by sharing self-help practices and narratives

of distress service users can create spaces of authority external to both the medical and the psychological model of mental health and challenge the logic of 'them and 'us' between mental healthcare providers and its recipients. Local peer support initiatives and virtual spaces that allow service users to position themselves as *experts-by-experience* by telling their stories of mental distress and its management in their own language can questions the assumptions of dominant discourses on mental health. However, such spaces may need to be created outside the remit of statutory mental health services to retain their emancipatory potential.

References

Aref-Adib, G., O'Hanlon, P., Fullarton, K., Morant, N., Sommerlad, A., Johnson, S., & Osborn, D. (2016). A qualitative study of online mental health information seeking behaviour by those with psychosis. *BMC Psychiatry*, 16(1), 232.

Barak, A., & Grohol, J. M. (2011). Current and future trends in internet-supported mental health interventions. *Journal of Technology in Human Services*, 29(3), 155-196.

Barak, A., Hen, L., Boniel-Nissim, M., & Shapira, N. a. (2008). A comprehensive review and a meta-analysis of the effectiveness of internet-based psychotherapeutic interventions. *Journal of Technology in Human Services*, 26(2-4), 109-160.

Beresford, P. (2005). Developing the theoretical basis for service user/survivor-led research and equal involvement in research. *Epidemiology and Psychiatric Sciences*, 14(1), 4-9.

Blaschke, C. M., Freddolino, P. P., & Mullen, E. E. (2009). Ageing and technology: A review of the research literature. *British Journal of Social Work*, 39(4), 641-656.

Bradford, S., & Rickwood, D. (2014). Adolescent's preferred modes of delivery for mental health services. *Child and Adolescent Mental Health*, 19(1), 39-45.

Chaiklin, S. (2003). The zone of proximal development in Vygotsky's analysis of learning and instruction. Vygotsky's educational theory in cultural context, 1, 39-64.

Christensen, H., Griffiths, K. M., & Farrer, L. (2009). Adherence in internet interventions for anxiety and depression: systematic review. *Journal of Medical Internet Research*, 11(2), e13.

Constantino, M. J., Ametrano, R. M., & Greenberg, R. P. (2012). Clinician interventions and participant characteristics that foster adaptive patient expectations for psychotherapy and psychotherapeutic change. *Psychotherapy*, 49(4), 557.

Coulter, A. (2006). Patient engagement: Why is it important. Healthy democracy: the future of involvement in health and social care, 27-35.

Crawford, M. J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *BMJ*, 325(7375), 1263.

Department of Health. (1999). National Framework for Mental Health: Modern Standards and Service Models for Mental Health. London: Stationary Office.

Department of Health. (May 2012). The power of information: Putting all of us in control of the health and care information we need Choice in health and social care. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213689/dh_134205.pdf.

Eysenbach, G., & Wyatt, J. (2002). Using the Internet for surveys and health research. *Journal of Medical Internet Research, 4*(2). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1761932/?report=classic

Eysenbach, G. (2005). The law of attrition. *Journal of Medical Internet Research*, 7(1), e11.

Greenberg, R. P., Constantino, M. J., & Bruce, N. (2006). Are patient expectations still relevant for psychotherapy process and outcome? *Clinical Psychology Review*, 26(6), 657-678.

Kidd, J., & Ziebland, S. (2016). Narratives of experience of mental health and illness on healthtalk. org. *BJPsych Bull*, 40(5), 273-276.

Kirby, P. (2004). A guide to actively involving young people in research. Publication no. http://www.invo.org.uk/wp-content/uploads/2012/01/ InvolvingYoungPeople2004.pdf). Retrieved 31st May 2017, from INVOLVE.

Lave, J., & Wenger, E. (1991). *Situated Learning: Legitimate Peripheral Participation*. Cambridge: Cambridge University Press.

Leigh, S., & Flatt, S. (2015). App-based psychological interventions: friend or foe? *Evidence Based Mental Health*, ebmental-2015-102203.

Meichenbaum, D. H. (1971). Examination of model characteristics in reducing avoidance behavior. *Journal of Personality and Social Psychology*, 17(3), 298-307.

Morahan-Martin, J., & Anderson, C. D. (2000). Information and misinformation online: Recommendations for facilitating accurate mental health information retrieval and evaluation. *CyberPsychology & Behavior*, 3(5), 731-746.

Murray, K., Pombo-Carril, M. G., Bara-Carril, N., Grover, M., Reid, Y., Langham, C., . . . Schmidt, U. (2003). Factors determining uptake of a CD-ROM-based CBT self-help treatment for bulimia: patient characteristics and subjective appraisals of self-help treatment. *European Eating Disorders Review*, 11(3), 243-260.

Nicholas, J., Proudfoot, J., Parker, G., Gillis, I., Burckhardt, R., Manicavasagar, V., & Smith, M. (2010). The ins and outs of an online bipolar education program: a study of program attrition. *Journal of Medical Internet Research*, 12(5), e57.

Noorani, T. (2013). Service user involvement, authority and the 'expert-by-experience' in mental health. *Journal of Political Power*, 6(1), 49-68. doi: 10.1080/2158379X.2013.774979

Patterson, S., Trite, J., & Weaver, T. (2014). Activity and views of service users involved in mental health research: UK survey. *The British Journal of Psychiatry*, 205(1), 68-75.

Proudfoot, J. G., Parker, G. B., Pavlovic, D. H., Manicavasagar, V., Adler, E., & Whitton, A. E. (2010). Community attitudes to the appropriation of mobile phones for monitoring and managing depression, anxiety, and stress. *Journal of Medical Internet Research*, 12(5), e64.

Repper, J., & Carter, T. (2011). A review of the literature on peer support in mental health services. Journal of Mental Health, 20(4), 392-411.

Riper, H., Andersson, G., Christensen, H., Cuijpers, P., Lange, A., & Eysenbach, G. (2010). Theme issue on e-mental health: a growing field in internet research. *Journal of Medical Internet Research*, 12(5), e74.

Tait, L., & Lester, H. (2005). Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment*, 11(3), 168-175.

Telford, R., Boote, J. D., & Cooper, C. L. (2004). What does it mean to involve consumers successfully in NHS research? A consensus study. *Health Expectations*, 7(3), 209-220.

van Spijker, B. A., van Straten, A., & Kerkhof, A. J. (2014). Effectiveness of online self-help for suicidal thoughts: Results of a randomised controlled trial. *PLoS One*, 9(2), e90118.

Vygotsky, L. (1987). Zone of proximal development. *Mind in society: The development of higher psychological processes*, 5291, 157.

Wood, D., Bruner, J. S., & Ross, G. (1976). The role of tutoring in problem solving. *Journal of Child Psychology and Psychiatry*, 17(2), 89-100.

Appendix 1: Journal of Mental Health Submission guidelines

Aims and scope

The *Journal of Mental Health* is an international forum for the latest research in the mental health field. Reaching over 65 countries, the journal reports on the best in evidence-based practice around the world and provides a channel of communication between the many disciplines involved in mental health research and practice. The journal encourages multi-disciplinary research and welcomes contributions that have involved the users of mental health services.

The international editorial team are committed to seeking out excellent work from a range of sources and theoretical perspectives. The journal not only reflects current good practice but also aims to influence policy by reporting on innovations that challenge traditional ways of working. We are committed to publishing high-quality, thought-provoking work that will have a direct impact on service provision and clinical practice.

The *Journal of Mental Health* features original research papers on important developments in the treatment and care in the field of mental health. Theoretical papers, reviews and commentaries are also accepted if they contribute substantially to current knowledge.

2014 Impact Factor: 1.570 - Now ranked 66/119 in Psychology, Clinical

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Submissions

All submissions, including book reviews, should be made online at Journal of Mental Health's Manuscript Central site at http://mc.manuscriptcentral.com/cjmh

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All books for reviewing should be sent directly to Martin Guha, Book Reviews Editor, Information Services & Systems, Institute of Psychiatry, KCL, De Crespigny Park, PO Box 18, London, SE5 8AF.

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Manuscripts should be typed double-spaced (including references), with margins of at least 2.5cm (1 inch). The cover page (uploaded separately from the main manuscript) should show the full title of the paper, a short title not exceeding 45 characters (to be used as a running title at the head of each page), the full names, the exact word length of the paper and affiliations of authors and the address where the work was carried out. The corresponding author should be identified, giving full postal address, telephone, fax number and email address if available. To expedite blind reviewing, no other pages in the manuscript should identify the authors. All pages should be numbered.

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Style and References: Manuscripts should be carefully prepared using the aforementioned Publication Manual of the American Psychological Association, and all references listed must be mentioned in the text. Within the text references should be indicated by the author's name and year of publication in parentheses, e.g. (Hodgson, 1992) or (Grey & Mathews 2000), or if there are more than two authors (Wykes et al ., 1997). Where several references are quoted consecutively, or within a single year, the order should be alphabetical within the text, e.g. (Craig, 1999; Mawson, 1992; Parry & Watts, 1989; Rachman, 1998). If more than one paper from the same author(s) a year are listed, the date should be followed by (a), (b), etc., e.g. (Marks, 1991a).

The reference list should begin on a separate page, in alphabetical order by author (showing the names of all authors), in the following standard forms, capitalisation and punctuation: a) For journal articles (titles of journals should not be abbreviated):

Grey, S.J., Price, G. & Mathews, A. (2000). Reduction of anxiety during MR imaging: A controlled trial. Magnetic Resonance Imaging, 18, 351–355. b) For books:

Powell, T.J. & Enright, S.J. (1990) Anxiety and Stress management. London: Routledge

c) For chapters within multi-authored books:

Hodgson, R.J. & Rollnick, S. (1989) More fun less stress: How to survive in research. In

G.Parry & F. Watts (Eds.), A Handbook of Skills and Methods in Mental Health Research (pp. 75–89). London:Lawrence Erlbaum.

Tables and Figures: Tables and figures should not be embedded in the text, but should be included as separate sheets or files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction.

Captions should be typed, double-spaced, on a separate sheet. All original figures should be clearly marked with the number and top edge indicated.

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Appendix 2: Ethics and Research Governance Approval Letters

Ethics 15-226

psychology-ethics

Fri 06/11/2015 08:02

To:Kristina Bennert <K.Bennert@bath.ac.uk>;

Dear Kristina Bennert

Reference number 15-226

The ethics committee have considered your application for the study above and have given it conditional ethical approval.

The committee have raised the following points which they would like you to attend to before giving the study full ethical approval:

1. Please provide a copy of the ethics approval once it is granted.

Please send the required information and revised document to me - you can do this by email to the Ethics Committee: psychology-ethics@bath.ac.uk

Please remember that you may not collect any data until you have ethical approval.

Yours sincerely,
Dr Michael J Proulx

15-226 Re: amendment for clin psych service improvement project

psychology-ethics

Sat 28/11/2015 12:08

To:Kristina Bennert <K.Bennert@bath.ac.uk>;

Dear Kristina Bennert,

Thank you for submitting details of these amendments. These are accepted by Chair's Action.

Best wishes
Michael Proulx
Chair, Psychology Research Ethics Committee

Avon and Wiltshire NHS
Mental Health Partnership NHS Trust

Avon and Wiltshire Mental Health Partnership AWP Trust
AWP Quality Academy
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0117 378 4238/ 07825 725296

Kristina Bennert,
Clinical Psychologist in Training,
Complex Psychological Interventions
Bristol Mental Health
AWP

Date: 24th November 2015

Dear Kristina

An online roadmap to psychological support for Bristol Mental Health Service Users
AWP Reference: E2015.014 Bennert

This letter is to confirm that your service improvement with evaluation is now approved and also provides you with our reference number.

If you do need any further support or information, please contact us using the contact details above, quoting our reference number for your study.

The importance of disseminating all evaluation work cannot be over emphasised. It is only by sharing our learning that we can improve services across AWP. For this reason, the findings of all evaluation work should be reported to the Evaluation team via email. The team will champion the results of service evaluations, and work with evaluators to ensure those results are disseminated and acted upon, and that the results of evaluations are reflected in future service delivery. The team will also work with evaluators to produce publications for the public domain.

I very much look forward to receiving the results of your evaluation in due course.

Yours sincerely,

Janet Brandling

Appendix 3: Service User Questionnaire

Bristol Mental Health caring open hopeful

Department of Psychology | University of Bath

NHS

Dear Service User,

My name is Kristina Bennert. I am a trainee clinical psychologist studying at the University of Bath. I am working together with service users to improve information about the psychological support available within Bristol Mental Health services.

We call this project 'Online Roadmap for Psychological Support'. It will become part of the new Bristol Mental Health website (http://bristolmentalhealth.org/). The Online Roadmap will feature experiences of service users and further links and information about the psychological support they have found helpful.

I hope you can help me with this project. I would like to hear from as many different people as possible, with or without experience of psychological support. The enclosed questionnaire will take about 10 minutes to complete.

Everyone who completes a questionnaire will be entered into a prize draw for a £50 shopping voucher!

Any information you provide will be treated confidentially. You do not need to give your name if you don't want to. You can enter your contact details for the prize draw on a separate tear-off slip.

Your views will help to ensure that the 'Online Roadmap' will be interesting and informative to service users like yourself.

Please return the questionnaire in the freepost envelope provided as soon as possible.

If you have questions about this project, please contact me on [redacted] or email kristina.bennert@nhs.net

Many thanks for reading this letter!

An Online Roadmap for Psychological Support for Bristol Mental Health service users

Service User Questionnaire, version 1.1, 19/10/2015

1. Do you have access to the internet? *Please tick **all** statements that apply to you.*

☐	No, I don't have internet access.
☐	I use the internet in public places such as libraries and cafés with wi-fi access.
☐	I have wi-fi internet access at home.
☐	I access the internet on my mobile phone.
☐	I access the internet on my tablet.

2. Do you currently use the internet to find out information and support for psychological problems? *Please tick **one** statement that best describes you.*

☐	No, I don't want to use the internet for this purpose.
☐	No, I don't know how to find trustworthy information.
☐	Yes, but I would like help with how to find trustworthy information
☐	Yes, I know how to find the things I want.

3. **How would you rate your <u>knowledge</u> about the following psychological therapies? You may not have heard of them. Would you like to know more?** *Please tick all that apply.*

Type of therapy	I know nothing about this therapy	I know a little bit	I know a fair amount	I know it really well	I would like to know more
CBT (Cognitive Behavioural Therapy)	☐	☐	☐	☐	☐
Family Therapy / Systemic Therapy	☐	☐	☐	☐	☐
Psychodynamic Therapy	☐	☐	☐	☐	☐
DBT (Dialectical Behaviour Therapy)	☐	☐	☐	☐	☐
ACT (Acceptance and Commitment Therapy)	☐	☐	☐	☐	☐
Mindfulness	☐	☐	☐	☐	☐
CAT (Cognitive Analytic Therapy)	☐	☐	☐	☐	☐
MBT (Mentalisation Based Therapy)	☐	☐	☐	☐	☐
Art Therapy	☐	☐	☐	☐	☐
STEPPS (Systems Training for Emotional Predictability and Problem-Solving)	☐	☐	☐	☐	☐
Other types of therapy (please write in)	☐	☐	☐	☐	☐

4. For which of these psychological difficulties would you like more information and support? *Please tick all that apply.*

Low mood	☐	Difficult relationships	☐
Worry and anxiety	☐	Developing healthy self-esteem	☐
Anger and aggression	☐	Intrusive thoughts and images	☐
Managing intense emotions	☐	Sleep problems	☐
Fear of social situations	☐	Hearing voices	☐
Panic	☐	Suspicious / paranoid thoughts	☐
Traumatic experiences	☐	Other (please write in)	☐

5. About which of these kinds of psychological support would you like to find out more information? *Please tick **all** that apply.*

One to one psychological therapy	☐
Group-based psychological therapy	☐
Peer group support / self-help group	☐
Self-help materials	
Books	☐
Worksheets and instructions	☐
Multi-media resources (e.g. video clips, relaxation CD)	☐
Online interactive therapy programs or mood apps	☐
Online chat groups or mailing lists	☐
Websites about specific psychological problems	☐
Other (please write in)	☐
I know as much as I want to about all of the above.	☐

6. Which kinds of psychological support have you <u>used yourself</u>?

*Please tick **<u>all</u>** that apply.*

I have had experience of…		If yes, can you describe what type?
One to one psychological therapy	☐	*e.g. psychodynamic*
Group-based psychological therapy	☐	*e.g. STEPPS group*
Peer group support / self-help group	☐	*e.g. AA group*
Online chat groups or mailing lists	☐	*Name or website address*
Websites about specific psychological problems	☐	*Name or website address*
Self-help materials, such as…	If yes, please tell us where you found resources that where helpful to you! (e.g. website, book or CD title, and so on)	
… Books	☐	*Title?*
… Worksheets and instructions	☐	*e.g. activity diary, tips for dealing with difficult situations*
… Multi-media resources (e.g. video clips, relaxation CD)	☐	*Title?*

7. Is there anything else about psychological support within Bristol Mental Health services or about the use of online psychological information and support that you would like to tell us? *Please write your comments below.*

---

8. About yourself

Please answer the following questions about yourself. This is to let us know whether the questionnaire has reached a wide range of different people.

a. Your age (roughly) *please write in* ___

b. Your sex (please tick) ☐ male ☐ female

c. What is your ethnic group? Choose one option that best describes your ethnic group or background

White

- ☐ English/Welsh/Scottish/Northern Irish/British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background, please describe _____

Mixed/Multiple ethnic groups

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed/Multiple ethnic background, please describe _____

Asian/Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background, please describe _____

Black/ African/Caribbean/Black British

- ☐ African
- ☐ Caribbean
- ☐ Any other Black/African/Caribbean background, please describe _____

Other ethnic group

- ☐ Arab
- ☐ Any other ethnic group, please describe _____

d. What is your religion? Choose one option that best describes your religion.

- ☐ No religion
- ☐ Christian (all denominations)
- ☐ Buddhist
- ☐ Hindu
- ☐ Jewish
- ☐ Muslim
- ☐ Sikh
- ☐ Any other religion, please describe _____

e. Which of the following best describes your sexual identity?

- ☐ Heterosexual
- ☐ Gay or Lesbian
- ☐ Bisexual
- ☐ Other (please specify) _____
- ☐ Prefer not to say

Thank you very much for completing the questionnaire!

You do not need to give your name. However if you would like to be entered into the prize draw for the £50 shopping voucher, please provide a name and telephone number or email address to contact you if you win.

Name: _____

Telephone number:_____

Email address: _____

✂----------

Would you like to be involved further?

Here are some other ways in which you can help with this project. Please tick all that apply:

- ☐ I have personal experience of using psychological support within Bristol Mental Health services and I would like to know more about taking part in an interview. Please send me an information pack.
- ☐ I would like to be informed when the Online Roadmap goes live on the Bristol Mental Health website.
- ☐ I agree to be re-contacted in Spring/Summer 2016 to give my feedback on the live version of the Online Roadmap.

If you would like to be involved further, please clearly write your name and address (including postcode) in the space below:

_____

_____

Please return this questionnaire to:

Kristina Bennert, CPI Team
Avon and Wiltshire Mental Health Partnership Trust
Callington Road Hospital
Marmelade Lane, Brislington
Bristol BS4 5BJ

Contact me at Kristina.bennert@nhs.net if you need a freepost envelope.

Appendix 4: Focus Group Schedule for Psychological Therapies Staff

Participant details:

Job title /grade / main therapeutic approaches / How many years since qualified? How many years in this service?

Key questions and prompts

1. **To what extend do you personally currently make use of online resources in your work with clients?**

   For yourself?

   To direct clients to?

   What kinds of online resources do you use regularly? e.g. psycho-education about problems, information, selfhelp, worksheets, other…?

2. **At what points in therapy do you think online resources could be used most effectively?**

3. **Views and possible concerns over clients' engagement with online resources?**

4. **For which psychological problems do you think it would be particularly helpful to have links to online psycho-education and self-help?**

5. **Which therapies currently offered within CPI would you think it most helpful to have online information about?**
   Factual info

   Peer testimony

6. **Views and concerns about service users who have had therapy telling others what it was like?**

Appendix 5: Cover Letter, Consent Form, Information Sheet and Interview Schedule for Gathering Service User Experiences

Cover Letter for Invitation to Take Part in an Interview about Personal Experiences of Psychological Support

Bristol Mental Health caring open hopeful

Department of Psychology | University of Bath

NHS

Online Roadmap to Psychological Support for Bristol Mental Health service users

Dear

Thank you very much for sharing your views and experiences as part of the "Online Roadmap to Psychological Support" Survey. I'm sorry it has taken such a long time for me to get back to you since you sent in your comments.

54 service users across Bristol took part in the survey. The winner of the prize draw was randomly selected from all replies with contact details and has now been notified. Thank you to everyone who took part!

Alongside the tick box responses, many of you were generous enough to provide free-text comments about your views and experiences with psychological support - some positive and sadly, quite a few also which were not so positive, but with clear ideas and suggestions of what you would like to change. I have typed up and anonymised all these comments and they will be passed on to appropriate service user representative channels over the next couple of months.

Your views on types of psychological support - what you know already and what you would like to know more about - will inform the next phase of the project - the development of contents to populate the pilot version of the "Online Roadmap".

I'm really pleased that so many people said they would consider sharing their experiences of different types of psychological support and agreed to be contacted with further details about taking part in an interview.

Please find attached a Participant Information Sheet and the 2-stage Consent Form to explain what taking part in an interview for the "Online Roadmap" project would involve.

- If you have provided a postal address, you will receive a hardcopy of this letter and the Information Sheet and Consent Form over the next few days.

- If you did not provide an address but would like to receive the information as a hardcopy, please send me a request with your address details, including postcode, to Kristina.bennert@nhs.net or to mobile [redacted]

Once you have had a chance to read through the information and to think about the advantages and disadvantages of taking part, I will contact via phone and/or email to find out whether you would like to take part in an interview.
If after reading the information, you feel that you do not wish to be contacted again, please drop me a text and email with your full name and I will take you off my contact list.

Many thanks again for helping with the "Online Roadmap" project!

Best wishes

Kristina Bennert
Clinical Psychologist in Training

Bristol Mental Health caring open hopeful

Department of Psychology | University of Bath | NHS

An Online Roadmap to Psychological Support for Bristol Mental Health service users

Participant Information Sheet - Interview

Why have I been invited for an interview?

You have told us that you have personal experience of using psychological therapies and/or online psychological support. You agreed that we could contact you to talk about whether you might want to share some of your experiences as part of the *Online Roadmap to Psychological Support* that is currently being developed on the Bristol Mental Health website.

The online roadmap will use personal stories by people like yourself to inform Bristol Mental Health service users about different kinds of psychological support available within Bristol Mental Health services and on the internet. The idea is that people with personal experience of mental health problems can tell others who experience similar difficulties what kinds of psychological support they have used and how this was helpful or unhelpful to them. We also hope that sharing personal experiences of psychological support in this way can help to ensure that the development of psychological services within Bristol Mental Health will be matched to service users' needs.

People's stories for the online roadmap will be made available as short text only, audio- or video-clips, depending on the wishes of the person donating their experiences.

Do I have to take part?

No, you don't have to take part in an interview. It is entirely voluntary. If you do decide to take part, and then later change your mind, you can withdraw without giving your reasons.

What will happen if I decide to take part?
We will contact you to agree a time and date convenient to you in a confidential setting to conduct a personal interview about your experiences of psychological support.
You will be asked to sign a written consent form (see enclosed form, Stage 1) to give permission for your interview to be video- and/or audio-recorded according to your wishes. You will be able to decide what you want to talk about and you will not have to answer any questions that you do not feel comfortable with. After the interview has been completed, you will be able to review your recording and ask for any parts of your story that you do not want to be shared with anyone else.

Are there any advantages from taking part?

Are there any disadvantages from taking part?

What should I do next if I want to take part?
Kristina Bennert, the clinical psychologist in training leading this project, will contact you via email or telephone over the next couple of days to find out whether you are still interested in taking part after reading this participant information sheet.

What if I have some questions?
Please feel free to contact Kristina me if you have further on the email or phone number below.

Study team contact details

Kristina Bennert
Clinical Psychologist in Training
Complex Psychological interventions Team
Avon and Wiltshire Mental Health Partnership Trust
Callington Road Hospital
Marmelade Lane, Brislington
Bristol BS4 5BJ
Mobile: [redacted]
Email: Kristina.bennert@nhs.net

Two-Stage Consent Form for Audio-Visual Recording

Bristol Mental Health caring open hopeful

Department of Psychology | University of Bath

NHS

An Online Roadmap to Psychological Support for Bristol Mental Health service users

Consent Form: Interview

Stage 1: Consent to record my experiences (to be completed before the interview)

Please initial box

1. I have read and understood the Information Sheet (version 1.0, dated 19th August 2015) for the above project and have had the chance to ask questions. ☐
2. I understand that the interview will be audio- or video-recorded according to my wishes. The data files will be stored securely in line with AWP Trust guidelines. ☐
3. I understand that I will have the chance to review my interview before parts of it are published on the Bristol Mental Health website and that I can change or delete things I have said that I do not want to be shared. ☐
4. I agree for my interview to be video-recorded / audio-recorded (delete as appropriate). I understand that I can decide how I want my interview to appear on the website at a later time. ☐
5. I understand that my decision to take part in the interview is voluntary and that I am free to stop participating at any time. ☐

Name of participant	Date	Signature
Name of clinical staff	Date	Signature

Stage 2: Consent to use my interview on the Bristol Mental Health website (to be completed after participant has had a chance to review their interview)

Please initial box

1. I have had a chance to review my interview (File Nr _____) and have marked for deletion any parts that I do not wish to be shared on the Bristol Mental Health website ☐

   Changes requested:

2. Yes ☐ (Clinical staff to append log with deleted interview sections to this form.)

   No ☐

3. I give permission for audio /video-clips from my amended interview to be included on the Bristol Mental Health website where they will be accessible to the general public. ☐

   I consent for my interview to be available on the website in the following format (please tick):

   text only ☐

   text and audio ☐

   text, audio and video ☐

4. I understand that if at any point in the future I want parts of my interview to be removed from the website I will need to contact Bristol Mental Health at bristolmentalhealth@nhs.net. I understand that it may take 4-6 weeks for my request to be processed and that during this time my material will still be available online.

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of clinical staff	Date	Signature

One copy to be kept with the participant's data files, one copy to be retained by the participant.

Appendix 6: Free-Text Comments from Service User Survey on Aspects of Service Delivery

These comments were received In response to the question “Is there anything else you would like to tell us about using Bristol Mental Health Services?”. They were shared at meetings with the Service User reference Group and the System Leadership Service User Representative.

Greater transparency around how to access psychological therapies

“[It would be important] to be realistic about waiting time before starting therapy. Difficult to find reliable information online - reliability of websites are very relevant to me now!”
Female, 69

“waiting times, assessment process”
female,29

"I have had much dealing with mental health for my son and myself on and off for many years. As a parent of a 33 year old son with mental health problems I have come across lots of boundaries (means barriers?) which I feel needs to be addressed.
Female, 54

"As there is little to no psychological support to the majority of Bristol Mental Health service users, anything would be an improvement. As a service user I find that having a support worker means I am unable to access certain services, but I am not well enough to NOT have a support worker and NEED to access these services, e.g. LIFT. I can't get funding for therapies, so nothing changes. There needs to be a rethink about how service users can access psychological services and info to help with our slow recovery."
Male, 51

"Accessing help is awful. It has taken over two years for me to get help, which hasn't started yet. I have been pushed from pillar to post and it has made me worse. I started needing CBT, then told DBT, then told mood management, then told CBT or DBT, then told CAT, then maybe CAT or DBT, now I'm back to CAT. It was been the most awful experience of my life and everything needs to change. It is a very damaging process."
Female, 37 “There are so many services and each refers you to the next. I think the services need to become more efficient and less bureaucratic. People with mental health problems just want to be helped in a crisis with practical (?) management and validation, rather than repeatedly being to make appointments with the right service.”
Female, 19

“In the 14 months I have been with Bristol Mental Health I still have NOT been given the opportunity of any free one to one psychological counselling. Neither am I told I am on a waiting list. My ill health justifies public funded counselling, but there are insufficient resources (finances £££) to make this happen. Talking therapies are an essential part of mental health treatment. My care co-ordinator (name) is brilliant as a practitioner and is giving me sessions to talk things through. That said, more funding for Bristol Mental Health = meds, counselling= better outcomes for longterm recovery. Inadequate resources for Bristol area of

Bristol Mental health - Ecom group, please take note!
Male, 49

Shortcomings of support received

"They helped me a little bit with daily living but nothing much. I have been with them for years and I don't get much health. I do not have psychotherapy- I don't even have proper meds. I feel bad, stuck and a lot worse when my mental condition is how (downward arrow) paranoia, depression, anxiety, psychosis, etc."
Female, 26

"In the past, I was referred for psychological support by my GP and after a brief face to face assessment (20 minutes) they would call me weekly and ask the same questions and wanted me to score the answers between 1 and 10. I found this depressing and unhelpful as it's hard to put my feelings into a score and found it wasn't addressing my problems. After a few weeks I stopped answering my phone."
Male, 42

"It is not sufficiently joined up with social needs and issues. Operates sometimes in a sort of vacuum. Psychological and social work experts need to talk to each other and put together a plan - "whole person" and "whole situation"
Gender not specified, 70

"I am a survivor of childhood abuse, and more recently, rape. Because of this I have developed BPD and PTSD. I am chronically suicidal, I have attempted 8 times. And constantly experience mood fluctuations, flashbacks, uncontrollable anger. There are not enough NHS services- here are so many and I have been bounced around multiple referrals and assessments but have never actually been given help in managing my PTSD."
Female, 19

"It takes a long time to access psychological support, whether it is through statutory or voluntary services. Psychological services, when statutory, the rooms are too clinical and not inviting, too formal. Voluntary psychological services: info is too basic and too short. This is my opinion."
Female, 39

"The lack of resources makes it very difficult to see someone and get help in the actual time of crisis"
Female, 40

"I think people should be able to choose their own therapist."
Female, 49

Things that have made a difference

"I was apprehensive about starting CAT but I'd say it was massively helpful and I miss that space to speak openly about myself in confidence. My therapist (name) at (site) was fantastic. She helped me learn so much about myself and behaviours and why I might have developed them, so I can see patterns and look for ways to change. She also introduced me to mindfulness which has been very helpful. I would definitely recommend the service.
Female, 36

"I find doing things (activities, exercise) helps my mental state of mind. If I'm doing nothing with my life, my mental state of mind can get worse. I think it is important to understand problems and work with things to overcome what could be really difficult. And I think people can turn their lives around from being on a real low. I think people should not dwell on things because it could drive you up the wall.

Male, 28

"I feel that mental health services replied quickly after my referral. Thanks."
Female, no age given

"I received a lot of information about my diagnosis from Mind. I also researched to find good reading material for me and my family. It is very rare to get info booklets given to you but they are available to pick up or if you request them. Link House give you a lot of information, handouts etc.
Female, 26

"Mental Health Services feel like the Cinderella of the NHS, though over the years I have had CBT, art therapy and psychotherapy on the NHS, so I have been "lucky". I have also had a good psychiatrist for about 8-9 years.I have a good "recovery navigator" at present, too."
Female, 68

"One example of a service that has really helped me is the Sanctuary at Old Market. Even though they are not officially a rape service when I came to them chronically suicidal because of my PTSD they do not tell me to go somewhere else. The listen and talk to me with compassion and respect. They talk to me face to face."
Female, 19

"I think the Bristol Mental Health website is clear and good to use as it has all the services listed and explained. I think it should be where every single group, website, service is listed, by category."
Female, 19

More information on support groups, carer groups and funding. My partner took lots of unpaid time off work due to my illness and we didn't - still don't- if we could gain help with rent etc. Financially information and support would be amazing!
More groups for trauma aftercare - for nice settings and possibly drug/homelessness awareness. As a student I have noticed lack of understanding and support in these areas.
Female, 23

"I have found psychological support sadly lacking at time though through the NHS I have had CBT, art therapy and 6 months of psychological one to one therapy. I am trying hypnotherapy at present.
Female, 69

Appendix 7: Impact Statement from the Mental Health Service Communications Officer

RE: feedback on impact of my work

CARR, Hannah (AVON AND WILTSHIRE MENTAL HEALTH PARTNERSHIP NHS TRUST)

Thu 11/05/2017 16:35

To:BENNERT, Kristina (AVON AND WILTSHIRE MENTAL HEALTH PARTNERSHIP NHS TRUST) <kristina.bennert@nhs.net>;

Importance: High

Hi Kristina,

I hope you're well.

How does the below sound? My memory of what we discussed last summer is a bit hazy now so please let me know if I've missed anything.

I began working with Ms Bennert in the summer of 2016 after she contacted Bristol Mental Health (BMH) with ideas about how the system could redesign its website. Ms Bennert proposed an 'online roadmap of psychological support for BMH service users' based on extensive research and feedback from a survey and interviews she carried out with people accessing BMH services.

The project was well-received when presented to staff, carers, service users and external stakeholders in focus groups and elsewhere. Ms Bennert attended one focus group and clearly explained the project to attendees and created a comprehensive handout for others to share elsewhere.

I incorporated several of Ms Bennert's proposals into a website redesign plan which was implemented in April 2017. For example:

- I have added a 'useful links page to the website after Ms Bennert suggested adding links to 'quality-checked online information and resources on the world wide web' to the website.
- I have redesigned the pages for each individual service so that they follow a set template and include clear information about who can refer to services. Ms Bennert suggested increasing transparency about referral pathways and criteria

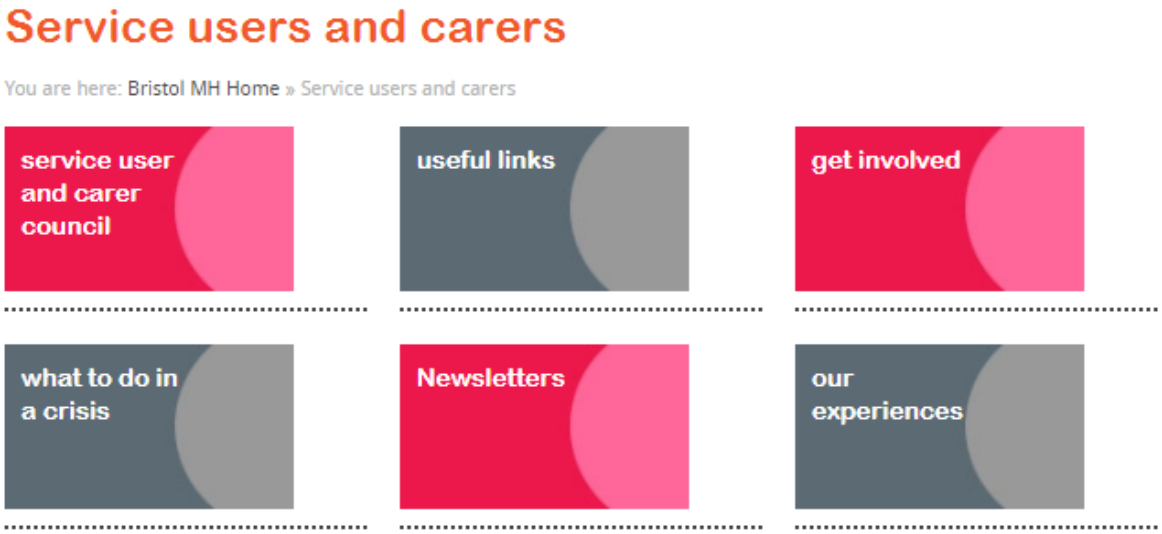
Ms Bennert's input to BMH's website redesign was really useful and has helped to create a website that is more accessible to users.

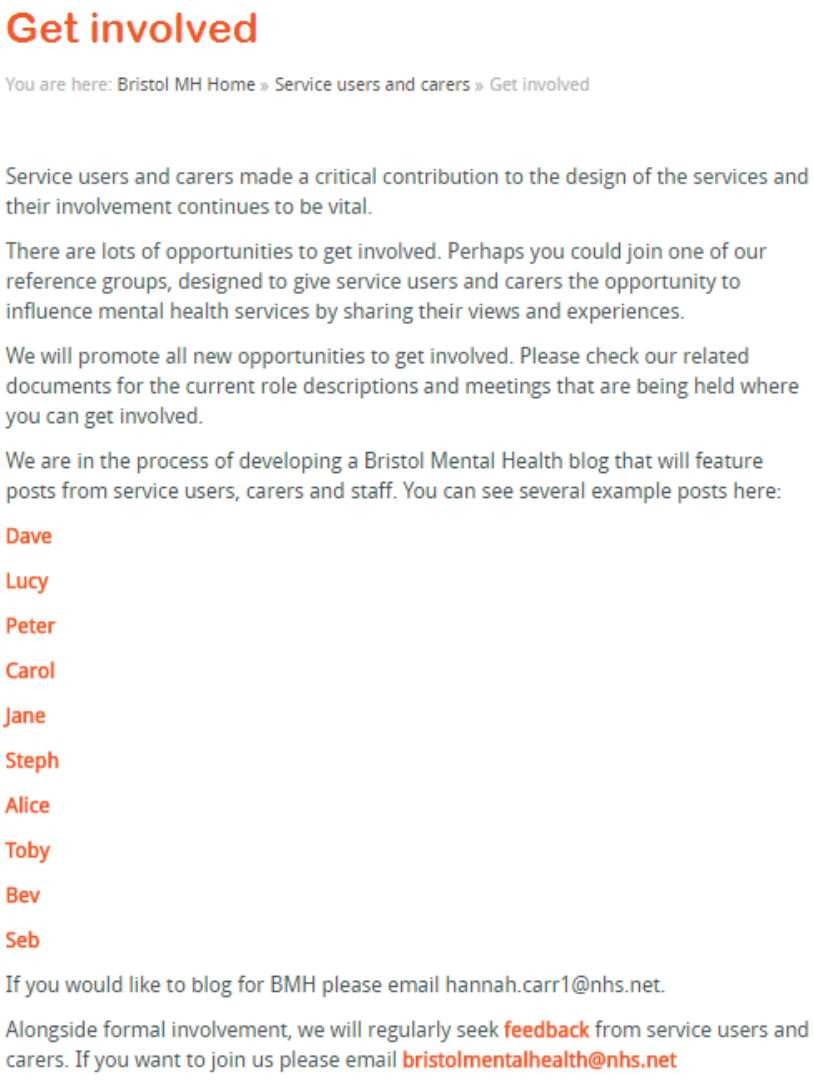
Best wishes,

Hannah Carr
Communications Officer
System Leadership

Bristol Mental Health
1 Colston Fort
Montague Place
Bristol BS6 5UB
[redacted]
email: hannah.carr1@nhs.net

Appendix 8: Screenshots of the Current Service Website





Case study

Carol discusses her experience of being a carer for her daughter and her involvement in projects to improve mental health care.

I've got four children, two sons and two daughters. My youngest daughter Laura became mentally unwell about three years ago, when she was 16. It was horrendous at the time.

She wasn't herself and seemed very depressed. She got counselling through her doctor and Child and Adolescent Mental Health Services (CAMHS) but eventually had to be sectioned. She was diagnosed with a form of bipolar and was in and out of hospital for two years.

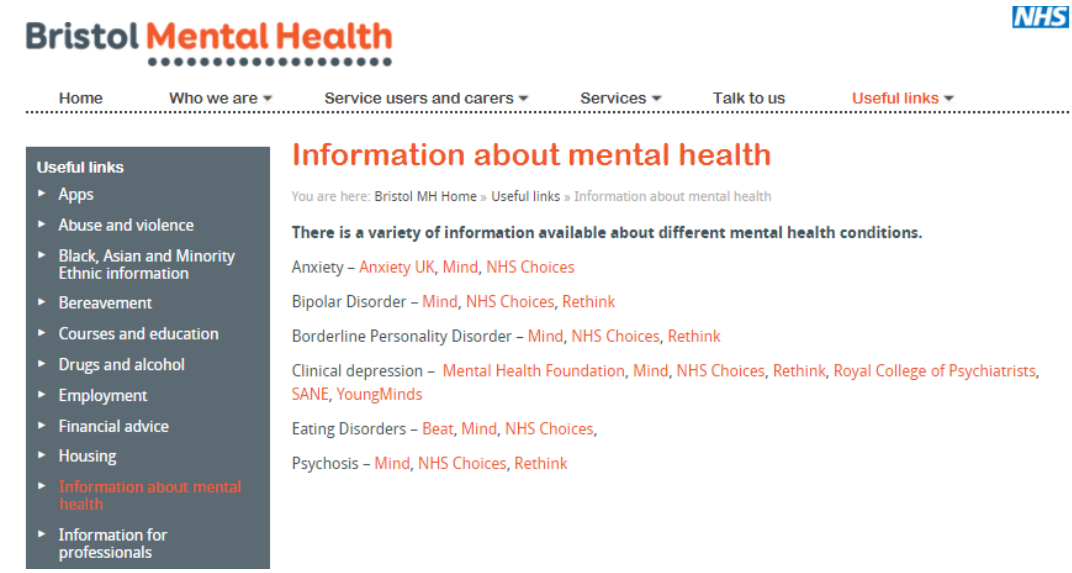
After being discharged she was supported by the Early Intervention In Psychosis (EI) Team who were brilliant. They saw us at home or in cafes, rather than in a hospital environment, which felt more comfortable and family-centred. Laura missed two years of school and sixth form but managed to catch up. Now she's at university and doing really well. She's still under the care of the EI Team and sees a Community Psychiatric Nurse which helps.

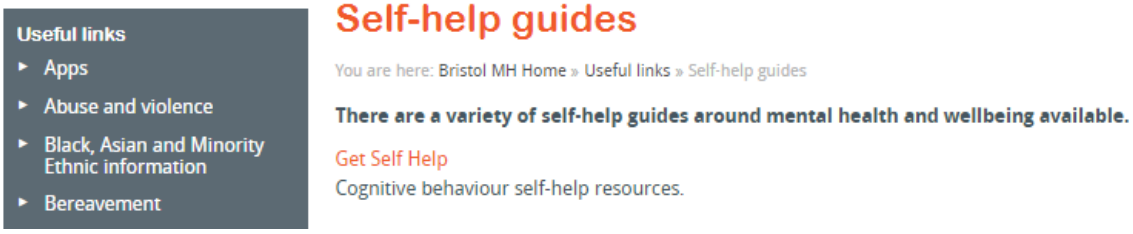
Since my daughter's been unwell I've got involved in different projects to help improve mental health care. I've been helping Joining the Dots (JtD) for almost a year now. It's a co-produced project involving BMH, service users and Otsuka Health Solutions that looks at supporting the provision of recovery focused care in Bristol services.

I'm part of the JtD service user carer group that meets every couple of weeks. I'm helping to develop a digital care planning tool, which we're designing to help health care

professionals and service users to work together to produce care plans. We're also involved in organising training to support service users to use the tool. I've appeared on a panel at an event Joining the Dots held too, where I spoke about my experiences as a carer. I like the way the project works. I feel fully involved in its development.

I've also taken several courses relating to caring and mental health, and joined groups about this too. I took part in a carers' course about dealing with psychosis, joined a Rethink course about coping as a carer and completed an online course about caring for people with psychosis and schizophrenia that I'd recommend. This helped me as my daughter had experienced psychotic episodes. It felt empowering to get involved with these courses. I currently run my own small business but am hoping that I can work in the mental health field or with families more in the future.





Useful links
- Apps
- Abuse and violence
- Black, Asian and Minority Ethnic information
- Bereavement
- Courses and education
- Drugs and alcohol
- Employment
- Financial advice

Mental health support groups

You are here: Bristol MH Home » Useful links » Mental health support groups

There are a variety of mental health support groups available in Bristol.

Self Injury Self Harm (SISH)
SISH is a Bristol-based community organisation which runs self help support groups for people who self injure. The groups offer a safe space where you can talk about your self harm and offer and receive support from others.

Useful links
- Apps
- Abuse and violence
- Black, Asian and Minority Ethnic information
- Bereavement
- Courses and education
- Drugs and alcohol
- Employment
- Financial advice
- Housing
- Information about mental health
- Information for professionals
- Learning disabilities and mental health

Podcasts

You are here: Bristol MH Home » Useful links » Podcasts

There are a variety of mental health and wellbeing podcasts available.

All in the Mind
A collection of podcasts exploring the limits and potential of the human mind

League of Awkward Unicorns
The League of Awkward Unicorns is a bi-weekly podcast covering mental health and emotional wellness, with a delightful combination of expertise, stories and irreverence.

Mental Health Foundation
This website offers a collection of podcasts and videos for your wellbeing.

Mood Zone podcasts
A series of podcasts to help you through times when your mood is low or when you're feeling anxious.

The Mental Illness Happy Hour
The Mental Illness Happy Hour is a weekly online podcast that interviews comedians, artists, friends, and the occasional doctor. Each episode explores mental illness, trauma, addiction and negative thinking.

Apps

There are a variety of apps that aim to improve people's mental health and wellbeing.

Breathe2Relax

Breathe2Relax is a free stress management tool which teaches breathing exercises. Breathe2Relax provides detailed information on the effects of stress on the body and instructions and practice exercises to help users learn the stress management skill called diaphragmatic breathing.

Emoodji

Emoodji is a free app from Mind that's designed to help students cope with the ups and downs of university life. The app allows you to track your mood over time and is full of tips to cope with different aspects of life, such as homesickness, money worries and exam stress.

ESC Student

ESC (Expert Self Care) Student offers students fast and discreet access to reliable health advice. It covers a range of health topics, including mental health.

Five Ways to Wellbeing

This app offers a practical way to help you feel good and function well in the world. You can use it to reflect on your wellbeing, set activities to help you improve your wellbeing and track your progress. Based on substantial research, use the Five Ways to Connect, Take Notice, Be Active, Keep Learning and Give your way to improved wellbeing. There's no daily dose or required level of work. You can use the app at your own pace to suit your life – you can even write and set your own personal activities.

Happier

Happier is an app that helps you stay more present and positive throughout the day. It acts like a personal mindfulness coach. You can use it to lift your mood, take a quick meditation pause or capture and savour the small happy moments that you find in your day.

Happy Healthy

Happy Healthy is an app that allows you to keep track of their lifestyle, exercise, nutrition and sleep habits so that you can become happier and healthier by gradually changing your daily habits.

Headspace

Meditation made simple. Headspace is an app which provides guided Mediation and Mindfulness for all levels. Meditation can help improve your focus, exercise mindful awareness, relieve anxiety and reduce stress.

Moody Me

You can track your mood with the Moody Me mood tracker to find out what makes you feel good. Keep a diary of your mood, note what affects it and record any treatments you're taking. Take pictures of what makes you happy and play them back for an instant lift, or see what makes you sad so you can better manage your mood.

MindShift

MindShift is an app designed to help teens and young adults cope with anxiety and to change how you think about anxiety. The app will help you learn how to relax, develop more helpful ways of thinking and identify active steps that will help you take change of your anxiety.

SAM: Self-help for Anxiety Management

SAM is a free app that will help you understand what causes your anxiety, monitor your anxious thoughts and behaviour over time and manage your anxiety through self-help exercises and private reflection. The 'social cloud feature' will enable you to share your experiences with the SAM community while protecting your identity. The app has been developed in collaboration with a research team from UWE, Bristol.

Complex Psychological Interventions Service

Telephone number: 0117 9195 680

Opening times: Monday to Friday, 9am-5pm

Who we are

The Complex Psychological Interventions (CPI) Service offers a range of activities to support psychologically informed care within the secondary mental health service. CPI has a strong presence in several Bristol Mental Health services. We also offer additional support, through supervision and training, to a variety of partner organisations.

CPI is comprised of multidisciplinary professions, including Clinical Psychologists, Arts Psychotherapists, Medical Psychotherapists and Specialist Nurses. Staff are located in a central hub (at Callington Road Hospital), as well as at community mental health team bases. CPI provides a range of services, both direct to clients, and supportive functions to staff teams that are designed to enhance the interventions delivered by teams, as well as contributing to the resilience and wellbeing of staff.

CPI offer complex assessment and formulation, as well as the provision of a range of therapies, including specialist CBT, psychotherapy, arts psychotherapist, family therapy, and Mentalisation Based Therapy (MBT) and Dialectical Behaviour Therapy (DBT). Therapy is offered both in individual and group formats.

"I felt that the team helping me was making me feel that things will get better. I feel like the group sessions were very helpful and made me not feel alone."

Quote from a service user.

Who can refer

CPI accepts referrals from secondary mental health care services. CPI does not accept referrals from GPs and individuals seeking mental health support.

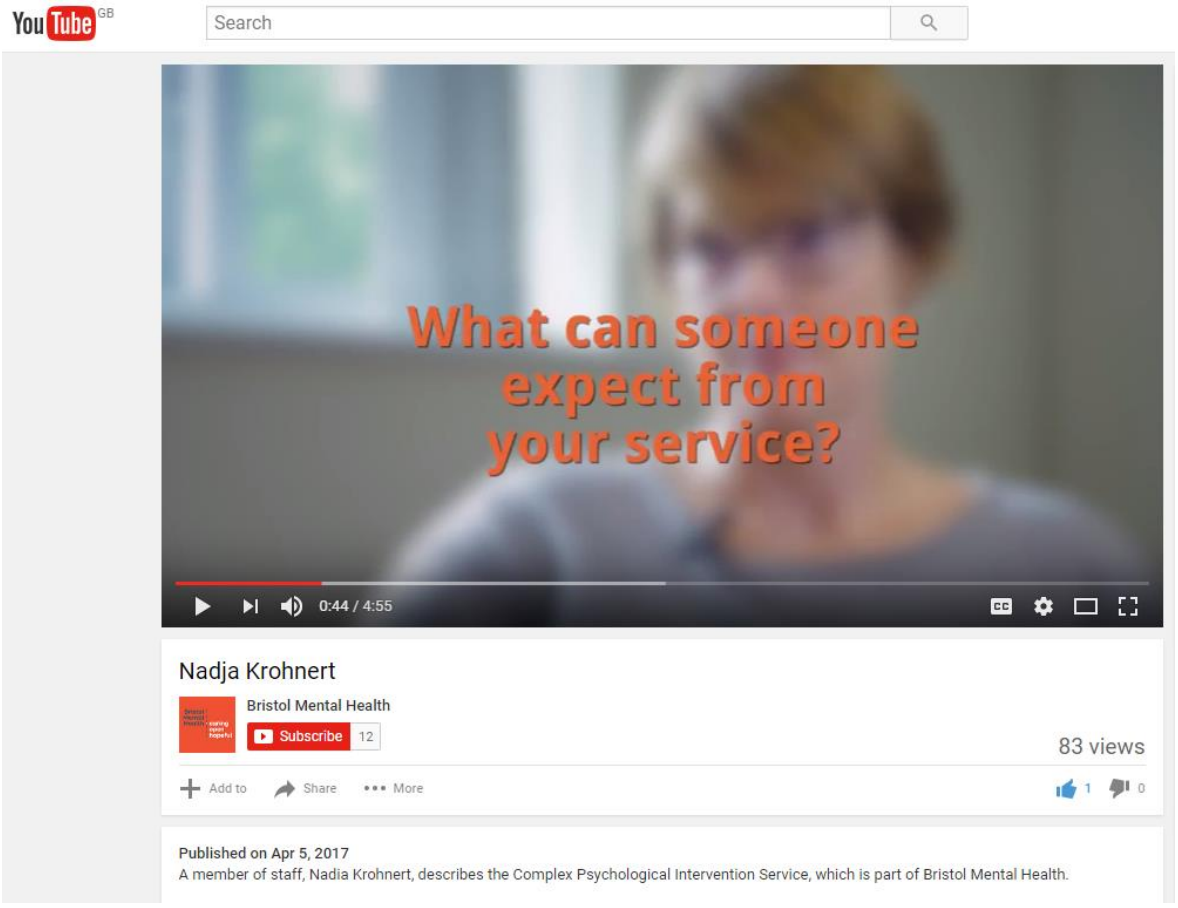
In crisis?

Find out more here

Provided by a partnership of

- SARI
- Wellspring Healthy Living Centre
- Southmead Development Trust
- Second Step
- Off the Record
- Nilaari
- Missing Link
- Brunelcare
- AWP

About our service



Systematic Literature Review

Men's Experiences of Disclosing Childhood Sexual Abuse in Adulthood: A Qualitative Meta-Synthesis

Kristina Bennert

Supervisor: Catherine Butler

Final Word Count: 8114 words

Acknowledgment:

I would like to thank Lucy Fiddick for acting as a second rater in the screening of abstracts and full texts for inclusion in this review.

Journal Submission:

To be submitted to Health Communication. The journal was chosen due to its interdisciplinary bridging of medical and social sciences and the congruence of its focus on the relationship between communication and health with the subject of abuse disclosure. Full description of scope and instructions for authors are included in the appendix.

"Because in speaking the words, you release the shame."

The Oprah Show ("200 Adult Men Who Were Molested Come Forward", screened on US TV, 5th Nov. 2010)

Childhood Sexual Abuse of Males

While public awareness about childhood sexual abuse (CSA) and its psychological impact has massively increased over the last 50 years and has led to the development of CSA-specific support services for women, until very recently, these developments have focused almost exclusively on female survivors (Easton, 2013). The sexual abuse of boys, previously believed to be rare (Browne & Finkelhor, 1986), has only gradually entered public awareness after various high profile scandals involving CSA in institutional contexts such as the Catholic Church, boarding schools, children's homes, the Boy Scouts movement and most recently, football coaching, across Europe, the US and Australia over the last decade (see e.g. *BBC News* 2010, 2017, *Der Spiegel*, 2010, *The Guardian*, 2016). Various researchers have suggested that recognition of widespread CSA of boys has also been hindered by societal attitudes that have viewed the sexual abuse of boys as a somewhat lesser concern, which - especially in case of female-perpetrated CSA - is frequently reframed as early sexual experimentation and a normal part of male socialisation (Deering & Mellor, 2011; Dhaliwal, Gauzas, Antonowicz, & Ross, 1996; Sally V. Hunter, 2009, 2010; Kia-Keating, Grossman, Sorsoli, & Epstein, 2005). Changing definitions of what constitutes CSA and difficulties in creating bias-free sampling methods have led to a wide variation in prevalence estimates for male CSA, ranging from 3-37% in studies conducted in the Anglo-American world (Dhaliwal et al., 1996). A more recent meta-analysis of CSA prevalence worldwide reports an overall prevalence of 7.6% for male CSA overall, with lowest rates in Asia (4.1%) and highest in Africa (19.3%), suggesting that around one third of CSA survivors are male (Stoltenborgh, Van Ijzendoorn, Euser, & Bakermans-Kranenburg, 2011).

Male Disclosure of CSA and Cultural Codes of Silence

Male CSA is thought to be under-reported in both childhood an adulthood (Dhaliwal et al., 1996). It has been estimated that only 10-33% of boys report CSA in

childhood, compared to 66% of girls (Holmes & Slap, 1998). A US national survey of adults (David Finkelhor, Hotaling, Lewis, & Smith, 1990) found that 42% of male survivors had never told anyone about their abuse, compared to 33% of females. A more recent US study based on a large anonymous online survey of 487 men recruited via the websites of three larger male survivor networks (Easton, 2013) found that 97% of respondents had disclosed their abuse at some point in their life, but that the majority of men made delayed disclosures in middle adulthood, with a mean of 21 years between the experience of CSA and initial disclosure. Only a quarter of respondents said they had disclosed abuse in childhood and only 15% said they had ever reported it to authorities.

Various authors have suggested that it may be harder for men to make disclosures of CSA as a result of gender socialisation (Alaggia & Millington, 2008; Dhaliwal et al., 1996; Kia-Keating et al., 2005). They argue that masculine norms of dominance, stoicism, strength and control over emotions act as barriers for men to disclosing traumatic experiences associated with intense distressing emotions and feelings of powerlessness and vulnerability. A view of men as victims of sexual abuse is incompatible with dominant socially constructed representation of men as aggressors and initiators of sexual activity, which precludes the supposedly feminine traits of passivity, helplessness and emotionality. This leads to culturally reinforced denial and avoidance of male CSA and a code of silence that makes it difficult for male survivors to develop integrated and functional gender and sexual identities (Kia-Keating et al. 2005). This dissonance between dominant discourses of stereotypical masculinity and personal lived experience may lead male survivors to adopt hyper-masculine behaviours as coping behaviours to reassert their maleness, including extreme aggression, homophobia, hypersexuality, over-control, emotional restriction or becoming perpetrators of physical or sexual violence themselves (Lisak, 1995).

Impact of CSA and Disclosure on Psychological Wellbeing

According to findings from a US national survey 20-40 % of male CSA survivors do not have “assessable psychological dysfuction” (Finkelhor et al., 1990). However, studies that examine the psychological impact of CSA consistently report poor mental health outcomes for a majority of male CSA survivors (Dhaliwal et al., 1996).

While many of the psychological sequelae of CSA, such as elevated rates of anxiety, depression, PTSD symptoms and feelings of shame, guilt and self-blame, are shared between male and female survivors, a number of researchers have suggested consequences of CSA that are more specific to men's experiences and thought to be compounded by dominant discourses of masculinity: these include homophobia, social isolation and emotional detachment, sexual dysfunction and confusion over sexual and gender identities (Dhaliwal et al., 1996; O'Leary & Gould, 2010). Briere, Evans, Runtz and Wall (1988) have argued that similar rates of mental health problems between men and women in view of comparatively less severe forms of CSA for boys suggest that males experience CSA as more traumatic and that this may be linked to lower disclosure rates. Empirical studies comparing men and women have found men to be more likely than women to express their emotional suffering through externalising behaviours and to use substances as a coping strategy (Sigurdardottir, Halldorsdottir, & Bender, 2012; 2014; O'Leary, Coohey, & Easton, 2010). Comparing mental health outcomes for male survivors and community controls, O'Leary and Gould (2008) found a tenfold increase in suicidal ideation and significantly higher rates of drug and alcohol misuse, violent and aggressive behaviour, anxiety, self-blame, loneliness and hopelessness.

There is a general assumption that disclosure of CSA is helpful and healing for survivors of abuse. However, helpfulness of disclosure crucially depends on quality of the response received. The *traumagenic dynamics model* (D Finkelhor, 1988) proposes that a supportive and validating response to disclosure is crucial to contain the traumatic negative effects of CSA. Conversely, dismissive, minimising or disbelieving responses to disclosure can re-traumatise survivors and further compound their sense of hopelessness, isolation and stigma. While in childhood, disclosure is usually an attempt to seek help and make the abuse stop, motivations for delayed disclosure in adulthood are likely to be different. Evidence from a mixed sample of CSA survivors suggest that while avoidant coping styles may be protective in childhood an adolescents, in adulthood non-disclosure and delayed disclosure were associated with more negative mental health outcomes (Sigmon et al., 1996, cited in Easton, 2013). Ullman and Filipas (2005, cited in Easton, 2013) found that the level of detail provided in CSA disclosure and negative social reactions were related to greater PTSD symptoms for both male and female CSA survivors. The fact that disclosure of abuse can in itself be re-traumatising is well-

documented in studies of sexual assault and has been labelled the *second assault phenomenon* (Washington, 1999).

Models of CSA Disclosure

Various scholars have sought to classify different types of disclosure according to their quality, context, motivation or intended consequences.

Alaggia (2004), based on a qualitative study with 24 male and female CSA survivors, focuses on disclosure in childhood and differentiates between accidental, intentional/ purposeful and prompted/elicited kinds of disclosure, as well as behavioural and indirect verbal attempts to communicate the presence of abuse and the intentional withholding of information in response to queries. Other scholars have emphasised that disclosure is an interactive process embedded within a pre-and post-disclosure stage (Staller & Nelson-Gardell, 2005, cited in Hunter 2011): the decision to tell is bound up with hopes and fears about the possible consequences of telling.

Adopting a perspective on disclosure as a life-long process, Hunter (2011) extends Allagia's typology of disclosure into adulthood and argues that the model need to include the addressee of disclosure and the motivation behind telling: telling the police is different from telling family members, which is different again from telling an intimate partner, friend, or therapist. Accordingly, Hunter distinguishes between purposeful disclosure made to authorities or family members with the intention of changing the relationship with the perpetrator, and selective disclosures made in the context of confiding in intimate relationships and friendships. A further distinction has been drawn between task-specific disclosure (i.e. identifying oneself as a CSA survivor to alert health professionals to specific needs and vulnerabilities, e.g. in the context of physical examinations) and general disclosure which involves sharing aspects of the CSA experience in greater depth, e.g. in the context of therapy (Teram, Stalker, Hovey, Schachter, & Lasiuk, 2006).

The conceptual utility of these distinctions is affirmed by a recent review on the dialogical process of disclosure in childhood (Reitsema & Grietens, 2016). The authors argue that disclosure is not a unidirectional transmission of information but an interactive

process in which the tellers' tentative expression is likely to be adjusted and modulated in response to the reactions of the addressee. This dialogical understanding of disclosure as an interactional process that unfolds over time in particular relational and social contexts and with relational and social consequences is in line with a social constructionist understanding of disclosure as a communicative act which has the potential to renegotiate social relationships and to bring about shifts in self-and other-understandings, or positionings (Van Langenhove & Harré, 1993). Within the social constructionist perspective (Shotter & Gergen, 1989), disclosure and non-disclosure can be understood as discursive practices that lay claim to particular social roles and subject positions whilst rejecting others, thereby contributing the narrative and interactional construction of identity (Bucholtz & Hall, 2005). The historical shift in terminology, referring to "survivors" instead of "victims" of sexual abuse provides an illustrative example of such discursive repositioning.

Quantitative Findings on Male CSA Disclosure in Adulthood

Easton's (2013) study presents the most comprehensive quantitative investigation on male CSA disclosure in adulthood to date. Based on an anonymous online survey with a non-clinical US sample of 487 male survivors aged 18-84, the study sought to move beyond disclosure as a binary 'yes/no' event and instead explored contextual aspects of disclosure across the life-course, including timing, delay, depth, purpose and initial addressees of disclosures, types of response received and links to mental health status.

The study differentiated between telling about the abuse and discussing it in-depth and found that the mean duration for participants between initial telling and in-depth discussion of the CSA experience was seven years. Older age of respondent and familial abuse were associated with greater delays in disclosure. Comparing response to disclosure in childhood and adulthood, a higher proportion of respondents said they had felt believed (96% vs 57%) and supported (34% vs (84%) when disclosing as adults. Partners and mental health professionals were the most frequently named initial addressees for disclosure (27 and 20%, respectively), whereas survivor organisations only accounted for 1%. While two thirds of respondents said they had discussed the abuse with a partner, 42% indicated that their most helpful discussion of the abuse had been

with a mental health professional. The study also found a positive correlation between number of years of delay until initial disclosure and levels of mental distress (measured as symptoms of depression, anxiety and suicidality) as well as greater levels of distress for those who had received unhelpful responses to initial disclosures and those who had not been able to discuss their abuse with partners.

While Easton's sample has limited representativeness (62% of respondents were abused by clergy; lower socio-economic and ethnic minority groups were underrepresented), it provides a helpful overview of overall patterns of male CSA disclosure in adulthood and highlights the important role played by mental health professionals as initial addressees and supportive discussants of disclosure. It also highlights the fact that male CSA survivors are a heterogeneous group and that participant demographics as well as type and context of CSA are likely to influence the disclosure process.

Meta-Synthesis of Qualitative Research

While there is now a growing body of epidemiological research on the impact of male CSA that is starting to close the gap with research on females, there is still a relative dearth of qualitative studies exploring men's experiences. Quantitative research is limited in its ability to advance a more nuanced understanding of men's experiences of the disclosure process and factors that may act as barriers and facilitators to disclosure, as it employs predefined, often binary or mutually exclusive categories in the attempt to objectively measure aspects of CSA and disclosure, such as severity of abuse or length of time of disclosure delay. Yet, it is the subjective meaning that male survivors assign to their CSA experiences and the beliefs and expectations they hold about others' perceptions of themselves and their possible reactions, as well as the impact of disclosure on their sense of self and relationships that will inform their decisions about whether to tell or not to tell.

Recognition that these issues are best suited to be explored within a qualitative paradigm, has led to a small but noticeable stream of qualitative studies on the experience of male CSA survivors over the past two decades. However, the majority of published studies that examine male survivors' experiences tend to involve selective and

predominantly clinical samples frequently recruited via a single route and are typically based on relatively small sample sizes. This makes men's experiences of CSA disclosure in adulthood a suitable topic for a meta-synthesis of existing qualitative research.

Meta-synthesis of qualitative research is a relatively recent approach with growing significance (Dixon-Woods, Booth, & Sutton, 2007) that fulfils parallel functions to quantitative meta-analysis in terms of summarising the current knowledge base on a given topic, but has important epistemological differences. Its aim is to synthesise findings from original research to generate a new understanding of a phenomenon that is greater than the sum of its parts (Campbell et al., 2003). Its techniques are interpretative rather than aggregative and deductive, seeking to describe, explain and understand phenomena instead of attempting to increase certainty about cause and effect relationships (Walsh & Downe, 2005).

Aims of the Review

This review provides a meta-synthesis of qualitative research on men's experiences of disclosing childhood sexual abuse in adulthood. Relevant terms were defined as shown in Table 1. Adopting a perspective on disclosure as a life-long and dialogical process (Hunter, 2011; Reitsema & Grietens, 2015), the review aimed to synthesise available qualitative data to address the following questions:

What are the barriers and facilitators to men's disclosure of CSA? What factors motivate and enable men to disclose in adulthood and what hinders them?

How do male survivors experience the process of CSA disclosure in adulthood across different contexts?

What is the impact of disclosure and non-disclosure for men's self-understandings, sexual and gender identity, social relationships and developmental trajectories towards healing from CSA?

Table 1: Definitions

CHILDHOOD SEXUAL ABUSE was defined following the NSPCC definition of *contact sexual abuse* (Radford et al., 2010). This includes any form of sexual contact (touching, kissing and penetration) but excludes sexual abuse or exploitation involving images or remote media. Further, CSA was defined as sexual activity of a child under the age of 16 with an adult (aged 18+), regardless of whether authors or research participants themselves labelled the activity as CSA. Sibling incest and sexual contact where all participants were children, was excluded.
DISCLOSURE IN ADULTHOOD was defined as any communicative act of the survivor sharing aspects of their CSA survivor status or CSA experience with others in written or verbal communication. Men's experience of disclosures made in childhood are only considered in terms of their impact on decisions about disclosure in adulthood (ADC). In order for CSA to be disclosed, the victim needs to first remember and recognise that abuse has taken place. Therefore, male survivors' sudden or gradually growing recognition of having been victims of CSA have also been considered in this review as they are as a crucial precondition for adult disclosure.
QUALITATIVE RESEARCH was defined as research based on the analysis of qualitative data (e.g. individual or group interviews or written comments provided to open-ended survey questions), which presents findings based on verbatim transcripts of participants' words and which provides verbatim quotes from the data to illustrate the identified analytic themes. This definition excludes papers that present research which analyses qualitative data with quantitative methods (e.g. content analysis that codes interview data for frequency of themes and does not provide verbatim quotes).

Methods

Search Procedure

The search terms, screening process and inclusion and exclusion criteria for the literature review were specified a priori. Due to the relative dearth of qualitative research on the topic of male CSA, the search terms for the initial retrieval of abstracts were kept deliberately broad to capture any studies that explored the experiences of male CSA survivors. It was assumed that perceptions and experiences relating to disclosure were likely to feature prominently in the accounts of CSA survivors, even if they did not constitute the main theme of the paper. The screening process therefore included a

second stage for which full texts were retrieved for all studies that reported on the experiences of male survivors to assess their relevance to the theme of CSA disclosure in adulthood. Screening was carried out by two raters independently. Instructions for the second rater provided detailed examples of types of papers and how to classify them on the basis of their relevance to the theme of disclosure (see appendix).

Electronic searching of six major literature databases was conducted using the following search string: *((male OR men) AND (survivor* OR victim* OR adult*) AND child* AND sex* AND abuse* AND (qualitative OR interview*)).* Specified terms were searched for in abstracts, titles and keywords. Further information on the rationale for the search string and choice of databases can be found in the appendix.

Identification of papers for inclusion in the meta-synthesis proceeded in three stages:

1. Systematic search of key databases and retrieval of citations (titles and abstracts) matching the search string criteria.

2. Screening of all downloaded citations following pre-specified inclusion and exclusion criteria by two raters independently to identify studies for full-text retrieval.

3. Screening of retrieved full-text papers against the more specific inclusion and exclusion criteria to establish (a) relevance to the theme of CSA disclosure in adulthood and (b) feasibility of extracting data specific to the experiences of male survivors in case of mixed samples.

Figure 1 presents a flowchart the number of articles retrieved and included or excluded during the search process and first and second round screening of abstracts and full-text papers, respectively. Included are all peer-reviewed publications identified by search string and articles identified from hand searching of references of key papers published up until 31st December 2016. Endnote reference software version 8 and QSR NVivo software version 11 were used to assist the screening process.

Citations from electronic searching were downloaded and duplicates removed, resulting in 910 abstracts which were screened independently by two researchers (KB and

LF) according to criteria as specified in Table 2. Inter-rater agreement for abstract screening was 94.8% and full-text papers were retrieved for all cases of disagreement.

Following the system proposed by Dixon Woods and colleagues (2007), during second round screening, the 76 full-text papers were assigned to one of four categories according to their relevance: key paper (N=8), satisfactory paper (N=12), fatally flawed paper (N=38) and irrelevant paper (N=18). 16 papers (20% of full texts) were double-coded by a second researcher to ensure consistency. Inter-rater agreement was 100%. Full details of second round screening criteria and category descriptions can be found in the appendix.

Figure 1: Flowchart of Search Procedure

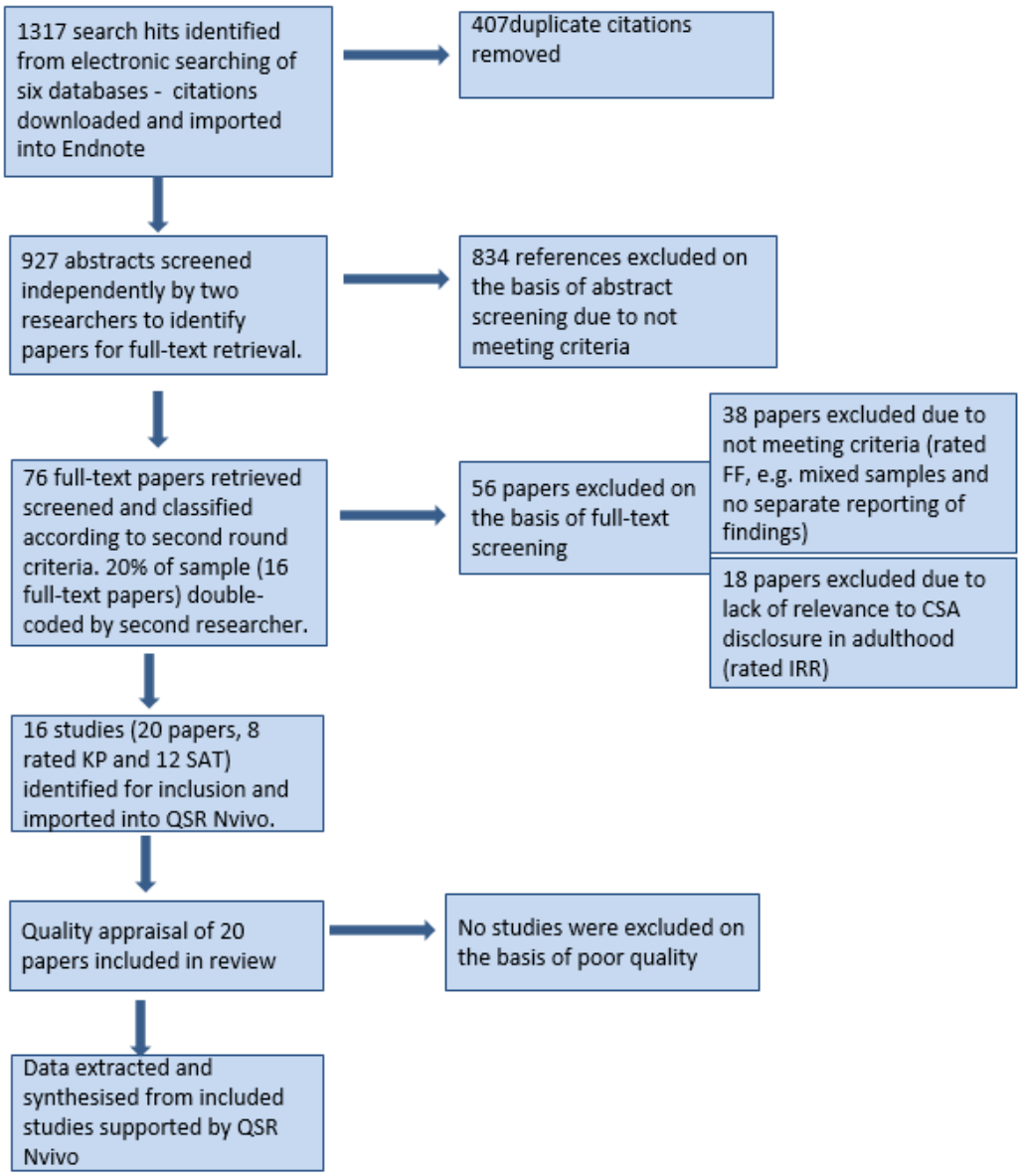


Table 2: Inclusion and exclusion criteria for screening of abstracts

	Inclusion Criteria	Retrieve to Decide	Exclusion Criteria
Type of publication	Peer reviewed publication	Unclear whether publication is peer-reviewed	Unpublished thesis or opinion piece (e.g. journal editorial)
Type of abuse	Study reports on contact sexual abuse	Study does not have an abstract (unless title is clearly not about men as victims of abuse)	Not about contact sexual abuse
Time of abuse	Sexual abuse occurred in childhood	Unclear whether referring to abuse in childhood or adulthood	Sexual abuse occurred in adulthood OR Not about men as victims of abuse (i.e. study with perpetrators as informants)
Method	Qualitative methodology (i.e. based on interviews or focus groups with informants) OR mixed methods study including use of qualitative methodology as described above	Study does not specify methodology	Methodology not qualitative (i.e. findings not based on qualitative analysis of interviews or focus groups): if too little detail to judge, mark as 'retrieve to decide' Single case studies of abuse survivors
Participants	Informants are adult male CSA survivors OR Informants are a mixed sample which includes adult male CSA survivors (e.g. male and female, adult & adolescent men, male survivors and professionals)	Study does not specify gender or age of informants OR it is unclear from abstract whether male CSA survivors constitute a clearly defined subgroup of participants	Female only sample OR Sample of family members or health professionals working with male survivors OR Single case study of male survivor OR experience of CSA is a finding of the study and not a criterion for participant recruitment (e.g. study of HIV positive men, some of whom were found to experience CSA)

Quality Appraisal of Included Papers

Whether the quality of studies that have been identified for a qualitative meta-synthesis should be formally appraised prior to their inclusion, and what may be the most suitable approach to objectively assess study quality remain contested topics amongst the qualitative research community (Dixon-Woods, Shaw, Agarwal, & Smith, 2004; Walsh & Downe, 2005). Several formal checklists and assessment frameworks have been drawn up which vary in prescriptiveness and comprehensiveness (Katrak, Bialocerkowski, Massy-Westropp, Kumar, & Grimmer, 2004). Regardless of choice of framework, Walsh and Downe argue that published reviews should include a list of the appraisal criteria employed as well as descriptive tables of summarises the aims, theoretical framework, design, and key findings of included studies. Such a table is provided in the results section.

Dixon-Woods and colleagues (2007) have demonstrated that quality appraisal employing established tools such as the Critical Appraisal Skills Programme (CASP) does not increase the reliability of outcomes. They advocate the use of prompt sheets tailored to the needs of the study at hand that can critical assessment of study components with methodological neutrality (i.e. not favouring any particular qualitative methodology) as the most parsimonious solution to the challenge of appraising qualitative research rooted within different theoretical traditions. Table 3 shows the aspect of study design and execution that were considered during quality appraisal and provides scores for the included studies. The prompt sheet used for quality appraisal is included in the appendix.

Unlike quantitative research, poorly executed qualitative research may still contribute relevant findings via the inclusion of themes arising from first order constructs (i.e. verbatim quotes from participants) even if the authors' analysis of the data is overly speculative or otherwise flawed. For this reason, no studies were excluded from this review on the basis of poor quality scores.

Table 3: Quality Appraisal of Included Papers

ID nr	Papers (authors/year)	Is the qualitative approach grounded in a clearly described methodological framework that suits the research questions?	Data collection - Are the following clearly described?			Data analysis - Are the following clearly described?			
			Recruitment methods and approach to sampling	Demographics and contextual details of participants	Methods of data collection	Methods of data analysis	Methods to enhance analysis reliability and validity	Contextualised quotes to illustrate themes	Relative saturation of themes
2	Alaggia (2005)	1	1	1	0	1	1	1	0
4	Alaggia & Millington (2008)	1	2	1	2	2	2	1	1
12	Denov (2003).	0	1	1	1	1	1	1	1
14	Dorahy & Clearwater (2012)	2	2	2	2	2	2	2	0
17	Draucker & Petrovic, (1996)	2	2	2	0	2	2	1	0
72	Draucker & Petrovic (1997)	0	1	1	2	2	1	1	1
74	Easton et al (2014)	0	2	2	2	2	2	2	2
19	Easton et al. 2015	0	2	1	2	1	1	1	0
20	Etherington (1997)	0	0	2	0	0	0	0	1
22	Fater & Mullaney, (2000)	2	1	1	1	2	2	1	0
23	Gagnier & Collin-Vézina (2016).	1	2	2	2	1	2	2	2
30	Gill & Tutty (1999)	0	1	2	2	1	2	1	1
65	Hovey et al. (2011)	1	1	1	0	0	1	1	0
33	Hunter (2008)	1	1	1	2	2	1	2	1
35	Hunter (2011)	1	1	0	1	1	0	1	1
37	Isely et al. (2008)	0	1	1	0	0	0	0	1
61	O'Leary & Gould (2010).	0	2	0	1	0	0	2	1
53	Sigurdardottir et al. (2012)	2	2	1	1	2	2	1	0
55	Sorsoli et al. (2008)	2	2	2	2	2	2	1	2
56	Teram et al.(2006)	0	2	0	1	0	1	2	0

Table 3: Quality Appraisal of Included Papers (continued)

ID nr	Papers (authors/year)	Data synthesis			Rating (Maximum total quality score of 22)
		Are interpretations well-grounded in the empirical data? (not just author opinion or overly speculative)	Do the authors consider possible biases and limitations arising from methods and potential impact on findings?	Does the paper provide conceptual integration of themes linked to previous findings and theories?	Score< 10=poor (red) Score=>10 satisfactory (yellow) Quality score=>15: good (green)
2	Alaggia (2005)	0	1	0	7
4	Alaggia & Millington (2008)	0	1	2	15
12	Denov (2003).	1	1	1	10
14	Dorahy & Clearwater (2012)	2	2	2	19
17	Draucker & Petrovic, (1996)	0	0	0	12
72	Draucker & Petrovic (1997)	2	0	1	13
74	Easton et al (2014)	1	2	2	19
19	Easton et al. 2015	1	2	1	12
20	Etherington (1997)	1	0	2	6
22	Fater & Mullaney, (2000)	2	0	1	13
23	Gagnier & Collin-Vézina (2016).	2	2	2	20
30	Gill & Tutty (1999)	1	0	1	12
65	Hovey et al. (2011)	2	0	0	8
33	Hunter (2008)	2	2	2	17
35	Hunter (2011)	2	1	2	11
37	Isely et al. (2008)	1	0	0	4
61	O'Leary & Gould (2010).	2	1	2	11
53	Sigurdardottir et al. (2012)	1	0	1	13
55	Sorsoli et al. (2008)	1	2	2	20
56	Teram et al.(2006)	1	0	1	8

Data Extraction and Synthesis Process

Qualitative meta-synthesis of the 20 included papers, reporting on findings from sixteen studies, employed an adapted version of meta-ethnography (Noblit & Hare, 1988). Included papers were uploaded into NVivo qualitative analysis software and coded into initial themes (second-order constructs) closely linked to those identified by the authors, alongside verbatim quotes (first-order constructs) to illustrate each theme. Themes identified across different papers were revised into a hierarchy of second-order themes and all papers were re-checked for second-order themes identified by other papers. Codes based on second-order constructs were further reviewed and mapped in relation to each other to aid the synthesis of overarching themes (third-order constructs) that sought to integrate the variability and potential contradictions present amongst second-order themes. For example, a second-order construct identified by several papers as a disclosure barrier was fear of being thought homosexual. However, one paper reported how male survivors who identified as homosexual were wary to disclose their abuse experiences as they did not want others to think that their sexual preference was 'caused' by their abuse experience. Men also worried that others might view them as potential perpetrators of CSA. The third order construct synthesised from these different themes was "fear of others perceiving adult sexual preferences as defined by the CSA experience" as a disclosure barrier. Table 5 in the appendix lists examples of second- and third-order constructs with illustrative quotes of first-order constructs.

Results

The synthesis of findings from the 20 included papers published in peer-reviewed journals between 1996 -2016 and based on 16 original studies, is reported below. Table 4 provides full details regarding country of study, aims, methodology, sample characteristics and key findings. Papers are referenced by their ID numbers.

Collectively, the included studies reported on the experiences of 692 male survivors of CSA, with ages ranging from 19-84 years[2]. It can be inferred that the majority of male survivors in these studies experienced CSA before 1985, a time when male CSA was not recognised as a significant issue. 460 participants came from one large

[2] Due to some papers only reporting age ranges, it was not possible to calculate an exact mean age across studies; however, where this information was provided, the majority of participants appeared to be in their late thirties and forties.

quantitative online community survey, which produced two papers (19, 74) based on qualitative analysis of participants' written responses to open-ended questions. The majority of studies included participants from a range of ethnic and socio-economic backgrounds, with different sexual orientations, living and family circumstances. However, less well-educated individuals and those from lower socio-economic and Black and Minority Ethnic (BME) backgrounds were under-represented in the sample as a whole. This may reflect the differential access to and utilisation of support services for these groups, especially in countries where psychotherapy has to be paid for.

Four studies purposefully selected participants to explore specific abuse contexts: female perpetrators (12); maternal abuse (20) and abuse by clergy (22,37). Twelve studies included participants who had been abused in a range of different contexts by both male and female perpetrators, inside and outside of family relationships. Studies varied greatly in the amount of details about the abuse provided as part of describing the sample but all employed selection criteria congruent with the definition of contact child sexual abuse.

Only eight of the included papers actually reported on men's experiences of making CSA disclosures, but all twenty reported on barriers to disclosure and thirteen considered the impact of disclosure and non-disclosure. The most thoroughly explored contexts of disclosure were psychotherapy (five papers) and other healthcare settings (six papers). Disclosure to partners or friends was mentioned rather than explored in details in six and four papers, respectively. Only three papers described instances of disclosure to family members in adulthood.

Findings from individual studies (second order constructs) were synthesised into third order constructs[3] and reorganised under four headings as below. The presentation of findings under each heading aims to provide an indication of the relative saturation of second order themes contributed by the individual studies. A more detailed breakdown of initially identified themes and the number of studies that identified each theme has been included in the appendix (Table A).

[3] Where the paper's focus of analysis was different from disclosure, first order constructs (i.e. participants' verbatim quotations) were translated directly into third order constructs).

Table 4: Details of Included Studies (N=16)

ID (papers)	Study	Country	Aims /Focus	Methodological framework	Participant details					Type of data	Key findings with regard to CSA disclosure in adulthood
					Numbers and diversity	Age range	Recruitment methods	Sample type	Abuse context		
2	Alaggia (2005)	Canada	To provide a qualitative exploration of the dynamics surrounding the disclosure of male and female CSA in childhood and adulthood	Long interview method (McCracken 1988) and grounded theory approach to data analysis	11 men , 29 women, 6% LGBT, 32% BME background, economically diverse	18-65 (for total sample)	Snowball sampling via community agencies and universities	Men and women, community sample	Abused by family member or by trusted adult with ongoing relationship (e.g. teacher)	One-off, in-depth interviews	Barriers to men disclosing CSA in adulthood include homophobia and not wanting to be seen as a victim. Men are less concerned than women about being believed or being blamed for the abuse (questionable).
4	Alaggia & Millington (2008)	Canada	To understand the lived experience of men sexually abused as boys and what life is like for them as CSA survivors in adulthood	Long interview method (McCracken 1988) Phenomenological reduction (Van Maanen 1997)	14 (8 Caucasian, 6 BME; 5 living with partner, 9 single/divorced, 10 heterosexual, 4 homosexual, 6 fathers) Men with serious mental health concerns were excluded	28-65 (Mean 41.1)	Snowball sampling, recruited via service agencies	Men only, Clinical sample	Familial abuse (8); Abused outside the family (10) Male perpetrator (14) Female perpetrator (4) Multiple perpetrators (4) All aged<9 when first abused	One-off, in-depth interviews	Repressed or fragmented memories, confusion around complicity and (fear of) homophobia in case of male perpetrators are barriers to male disclosure in adulthood. Therapists have a responsibility to ask male clients about CSA when this is not the presenting problem.

12	Denov (2003)	Canada	To explore the experiences of male and female CSA survivors of disclosing female-perpetrated abuse to professionals	Thematic analysis - no specific framework identified (citing Mason; Glaser and Strauss, Huberman)	7 (of 14)	23-59 for total sample	Referral by professionals working in CSA and self-selected in response to posters in service	Men and women, clinical sample	Abuse by female perpetrator. Details for participants of both genders: female relatives (10) un-related females, e.g. babysitter (4) single events (2) ongoing abuse (12)	One-off semi-structured interviews	Quality of response to ADC has crucial impact on survivors' wellbeing. Supportive responses including validation of CSA experience. Minimising and disbelieving responses result in secondary traumatisation. Findings confirm professional ambivalence to female sex- offending found in previous studies.
14	Dorahy & Clearwater (2012)	New Zealand	To examine the experiences of shame and guilt in adult male survivors of CSA	Interpretive Phenomenological Analysis (IPA, Smith and Osborn, 2003)	7 (all White European descent; 2 married , 2 single, 2 separated	37-64 (mean age 45.9)	convenience sample (pre-existing therapy group)	Men only, clinical sample	Mixed (5 familial, 2 non-familial, 5 male perpetrator only, 2 male and female familial perpetrators)	One off focus group (90 minutes) held with existing group therapy members	Shame inhibits help-seeking. Avoidance of close relationships and social isolation is motivated by fear of exposure. Negative past responses to disclosure and uncertainty about response act as barriers to disclosure both in informal and professional settings.
17, 72	Draucker & Petrovic (1996, 1997	US	(17) to generate a framework of healing by male CSA survivors (72) to describe and summarise the advice male CSA survivors would give to therapists	Open-ended /unstructured interviews; grounded theory approach to analysis (72) thematic content analysis	19 (2 Hispanic, 7 married, 4 divorced, 8 single, 9 fathers, several homosexual)	23-55	via treating clinicians and public adverts	Men and women, clinical and self-help	Mixed (familial, trusted adults, stranger)	Mix of one-off individual interviews (8 face to face, 2 telephone) and group interviews with existing therapy groups(2)	(17) Integrates the themes emerging from interviews into metaphor of male healing from CSA as 'breaking free from the dungeon'. Highlights implications for clinical practice, such as special attention to men's language and depth of emotion. (72) Describes male survivors' experiences of positive and negative responses to disclosure in therapy context via a typology of therapist types.

19, 74	Easton et al. (2013)	United States	(19) To describe turning points in life-course trajectories, in a large community sample of male CSA survivors (74) To examine barriers to disclosure of CSA in the same sample	Qualitative Content Analysis (Miles and Huberman, 1994) of written responses to open-ended question in online survey	460 men, 10% BME members, 68% living with partner	19-84 (mean 50.7)	Purposive sample of 460 men (10% BME)	Men only, community sample (85% were members of survivor organisations)	62% abuse by clergy, 5% female perpetrator, 11% familial abuse, 20% other ongoing relationship with perp, 10% perpetrator was aged <18	Written responses to question: "why may it be difficult for men to tell someone about the sexual abuse?"	(19) Identifies three broad categories of turning points: influential relationships, new meanings and insights (including cognitive realisation of abuse and necessity to change and action-oriented communication (including disclosure and pursuit of justice) (74) Identifies three overlapping domains of barriers to disclosure: personal (e.g. shame, naming experience as abuse), interpersonal (e.g. mistrust, past responses) and socio-political (masculinity discourse, limited resources).
20	Etherington (1997)	UK	To describe male survivors' psychological defence mechanisms and to argue how prevalence and outcomes of male CSA are affected by male socialisation	Not specified in paper (refers to book)	7 men (5 heterosexual, 1 bisexual, 1 asexual; 1 married, 2 single, 4 divorced, no BME)	29-56 (mean age 39.8)	Purposive subsample drawn from larger study, clinical sample	Men only, clinical sample	Maternal abuse	One-off, in-depth interviews	Male socialisation creates additional barriers to disclosure for men abused by their mothers in terms of recognising the abuse and fears of being judged.
22	Fater & Mullaney (2000)	United States	To describe the lived experience of male survivors of CSA by clergy	Phenomenology	7 men, 5 married, 1 re-married, 1 single (no further demographic info)	28-48	Self-selected, Recruited via abuse survival network	Men only, community sample	Abuse by male clergy (same 3 perpetrators for 7 participant survivors); abuse duration: one off experience to many years	6 face to face and one telephone interview, conducted by a pair of researchers	Adult non-disclosure rooted in punitive responses to childhood disclosure and continued fear of reprisals. Repressed memories, feelings of complicity and status of the church as barriers, wanting to protect others as motivations for adult disclosure.

23	Gagnier & Collin-Vézina (2016)	Canada	To explore the diversity in disclosure process of male CSA survivors	Phenomenology and interpretative method	17 men (subgroup of larger mixed sample of 69), 8 with degrees (no info on ethnicity, family status or sexual orientation)	19-67 (mean 47)	Purposive subsample, recruited via community and mental health organizations for CSA victims in 4 cities	Men only, clinical sample	Multiple perpetrators (8) male perpetrator (9), female perp (6) abuse started <=age 10	Telephone interviews, lasting between 30-90 minutes	Summarised themes under disclosure trajectories and disclosure experiences: Negative stereotypes contribute to delayed disclosure of abuse in adulthood. Qualities of positive and negative responses to disclosure across contexts are described.
30	Gill & Tutty 1999	Canada	To explore the beliefs of male CSA survivors with respect to their victimisation in ways that can inform clinical practice	Atheoretical (using grounded theory sampling strategy and content analysis methods for data analysis)	10 (8 heterosexual, 2 homosexual, 6 living with partner, 4 single)	27-50 (mean 37)	Referred from local counselling services	Men only, clinical sample	First abused between age 4-10, duration 3 months – 7 years. Male perpetrators (9) female perpetrator (5), multiple independent perpetrators (8).	One-off face to face two hour interviews	Society's refusal to accept men as victims provides a barrier to CSA in adulthood. Men often don't disclose even to intimate partners and experience difficulties forming close relationships, isolation and sexual difficulties as a result. Therapists need to enable men seeking help for relationship problems or substance misuse to disclose possible CSA.
33, 35	Hunter (2008, 2011)	Australia	(33) to explore how men and women construct a sense of self through narrative following early sexual experiences that meet criteria for CSA (35) to develop a fuller understanding of the process of CSA disclosure throughout the lifecourse	Purposive sample, Narrative Inquiry (Fischer-Rosenthal, 2004)	13 (of 21, mixed male/female sample)	aged 25-70 (information whole sample)	Self-selected in response to press release and radio adverts	Men and women, non-clinical sample	Mixed- sexual contact with an adult aged 15 or younger. Participants did not necessarily label their experiences as CSA.	One-off, in-depth narrative interviews	(33) Identifies four types of narratives about early sexual experience and highlights gender differences in making sense of these. Increased public awareness and media reports of CSA prompted some participants to reappraise their experiences and possible links to difficulties they had experienced.

37	Isely et al. (2008)	United States	To examine the impact of CSA on men assaulted by Catholic clergy and give voice to this group	Not described	9 men from middle-class Catholic backgrounds, college-educated	31-67	Recruited via network of survivors of abuse by priests (no further detail provided)	Men only, community sample but 8 of 9 had had therapy	Abused by ordained Catholic ministers aged 15 or younger	"audio-recorded conversations" (no further details)	CSA by clergy is a developmental insult with life-long negative effects for victims. Barriers to disclosure in adulthood included fragmented memories, wanting to forget, shame and fear of reprisal.
61	O'Leary & Gould (2010)	Australia	To illuminate previously identified variables associated with men's long-term coping and explore what helps men in recovering from CSA	Thematic analysis (atheoretical)	39 (men only), no info on diversity	No info provided	Self-selected, opportunistic clinical sample, recruited via support services for CSA survivors	Men only, clinical sample	Mixed – not further specified	One off face to face interviews, lasting between 15-60 minutes	Disclosure can facilitate switch from use of unproductive to productive coping strategies, advice given to other men and to health professionals of how to better support male CSA survivors.
53	Sigursdottir et al. 2012	Iceland	To explore how male survivors' experience of CSA has affected their health and well-being in adulthood	Phenomenological analysis based on Vancouver School	7 men, all fathers (6 non – custodial)	30-55	Self-selected via adverts in CSA survivor services	Men only, clinical sample	Not specified. Abused started age 4-5	In-depth interviews x 2, 1-4 months apart	Men lived in repressed silence with intense feelings of shame and self-blame, which made them feel isolated, unable to form close relationships and suicidal. Fear of being perceived as a potential perpetrator was key barrier to disclosure.
55	Sorsoli et al. (2008)	United States	To examine barriers to disclosure across multiple domains of experience and across the life-span. (Participants were part of a larger sample recruited to explore resiliency).	Constructivist-interpretivist (Ponterotto, 2005) and feminist orientation, grounded theory approach adopted for coding data	16 (9 heterosexual, 5 homosexual, 2 bisexual)5 BME background, 14 with tertiary education	24-61	Recruited via therapists and via flyers in community and mental health services for survivors of CSA.	Men only, clinical sample	Abuse occurring in ongoing relationships (12 familial, 4 professional care-takers, e.g. teacher)	Interviewed twice one week apart, interviews lasted 2-3 hours each	Participants described personal (lack of awareness or emotional readiness, avoidance, shame), relational (fear of negative repercussions, isolation) and socio-cultural (homophobia, male victimisation as sociocultural taboo) reasons for their struggles with disclosure - barriers exist across multiple domains of experience and across the lifespan.

56, 65	Teram et al. 2006, Hovey et al. 2011	Canada	To provide a gender-based analysis of the healthcare experiences of male CSA survivors to help inform sensitive healthcare practice	(56) no theoretical framework specified (65) grounded theory and action research	49 men (7 BME background; 50% living with partner, 50% single)	24-61 (mean age 41)	Self-selected sample, Recruited via posters in counselling and support agencies	Men only, clinical sample	No information provided	Interviews and focus groups	Gender-based difference exist relating to perceptions of victimhood and manhood: guilt, shame, homophobia and expression of vulnerability. Male-centric communication by healthcare staff is proposed as a way of addressing the healthcare needs and barriers to seeking care for male CSA survivors. Includes guidance for therapists.

Barriers to Disclosure in Adulthood

The biggest most frequently identified barrier to male disclosure of CSA were feelings of shame and self-blame, which were highlighted in all papers. While these emotions are well-documented in the literature on female CSA survivors, shame was described as more pervasive for men and closely linked to homophobia and dominant discourses of masculinity. Six papers described this shame as arising from a deeply rooted cultural taboo around male CSA (53,55,74) and the perception of a violation of cultural norms for victims themselves and society at large (20,61,56). Men's accounts suggested that their feelings of shame and self-blame had been further exacerbated by invalidating responses to previous disclosure attempts in both childhood and adulthood (23,55,74).

Ten papers reported on male survivors' fear of being labelled as homosexual if they were to disclose abuse by a same-sex perpetrator. Related fears included being seen as weak, a victim, not a 'proper' man (eight papers), and fear of being blamed for the abuse (three papers) or judged and stereotyped in other undesirable ways (six papers). A couple of papers mentioned survivors' doubts and fears over their own possible homosexual orientation as a further barrier specific to men (2,74) Two papers (4,56) made links between men's confusion over their role in the abuse – i.e. feelings of self-blame and complicity - and the visible physical signs of male arousal –erection and ejaculation - which led male survivors to believe that they must have wanted the abuse to happen or that it must have meant they secretly desired homosexual relations. Seven papers specifically commented on men's fears of being seen as potential child abusers themselves as a huge barrier to disclosure. However, men abused by female perpetrators were also reported to worry about being ridiculed and having their painful experiences minimised, dismissed or reframed as desirable (12,56)

Fear of not being believed was identified as a barrier to disclosure more typical amongst female than male survivors (2). However, it was highlighted as a significant barrier in the accounts of men abused by clergy, who were also the only group that mentioned fear of reprisals as a barrier to disclosure in adulthood (22,74). Several other studies mentioned fear of uncertain consequences and loss of control as barriers (14,65) including uncontrollable emotions in themselves as well as fear of causing upset to others, e.g. elderly family members (74,33,35,55).

Before adult survivors of CSA can consider disclosure, they need to (a) remember their CSA experiences with a degree of certainty and (b) recognise the nature of these experiences as abusive. Eight papers identified male survivors' repressed or fragmented memories of abuse as a barrier to CSA disclosure. Three papers (14,37,74) reported how some men felt doubtful about whether their memories were accurate and described them as having a "surreal quality". Some said they had repressed memories for many years as associated emotions had been too painful. Not being able to tell a coherent story about the abuse thus became a barrier to disclosure. Three papers (4,33,74) described substance misuse as a common method for male survivors to block out painful abuse memories. Conversely, recovery from substance misuse was described as a triggers for the surfacing of repressed memories. Importantly, men in these studies also said that they had required the support of therapists or significant others to link their difficulties as adults in the realms of substance misuse, close relationships and sexual functioning to their experience of CSA.

Five studies highlighted men's difficulties to recognise and label what had happened to them as CSA, in particular if they were abused by a female perpetrator (20,56) or by a member of the clergy (37). Men abused by female perpetrators described societal stereotypes of females as "nurturers not abusers", and males as the instigators of heterosexual sexual activity as barriers to disclosure. Some men abused by their mothers found it difficult to perceive them as perpetrators and preferred to describe the abuse as "over-loving" (20). Similarly, the societal status of the clergy and its association with godliness, along with male survivors' deep sense of shame and complicity made it difficult for male survivors of clergy-perpetrated abuse to name their experiences as CSA (37,74).

Some participants in the online community survey (19,74) and the study that had recruited for "early sexual experiences" instead of CSA (33,35) stated that they had interpreted their experiences as a normal part of growing up and did not feel personally affected by the abuse, therefore disclosure of these experiences in adulthood did not seem relevant to them.

Facilitators of Disclosure

The motivation to disclose CSA will be influenced by adult survivors' beliefs about how CSA has affected them and what is to be gained by sharing this information. Interestingly, Hunter's study identified another group of participants, who acknowledged that they had been deeply affected by their CSA experience, but nevertheless actively decided against disclosure as a way of rejecting a 'survivor' identity and the societal assumptions attached to this label. Conversely, studies based on clinical samples reported gradual realisation of the personal impact CSA had had on them and the belief that disclosure constituted an essential step towards healing as a key motivation for men to come forward and disclose their CSA experiences in psychotherapy and self-help groups (4,17,22,61,56). A couple of studies reported how life-course events, such as death of the perpetrator or birth of a child, could act as turning points for male survivors, prompting them to want to actively engage with their CSA experience instead of continuing to avoid it (4,33).

Other motivations for men's disclosures in adulthood included: fear of becoming a perpetrator (2), helping others to face up to abusive experiences (23,30) and helping themselves to form positive survivor identities by "finding a voice" in writing and public speaking (23), bringing perpetrators to justice (35,61), wanting to effect change in family relationships (17,55) and on a practical level, using selective disclosure to inform health professionals that touch during physical examinations might be triggering (56).

Several studies described CSA disclosure in adulthood as a painful and terrifying, though ultimately rewarding process - one study employed metaphors of "escape from the dungeon" and "the perilous road to freedom" (17). They emphasised the amount of trust and courage men required to disclose in view of the previously discussed barriers and identified a number of factors that could help to ease disclosure for male survivors. These included: presence of close trusting relationships and social support (53,61), clinicians proactively asking about CSA when male clients present for other problems and men's confidence that recipients could handle the information (30,53,56,65), contact with other male survivors who had successfully disclosed (14,23,61), increased public awareness and media reports about CSA (22,23,33,61,65) and visibility of CSA survivor services that were explicitly inclusive of men (56).

Positive and Negative Experiences of Disclosure

Only five papers reported on positive disclosure experiences, all within a therapeutic context. Participants in these studies described qualities of supportive responses which included: being believed and validated (12, 14, 23, 61), empathic attitude (12), treating the abuse seriously (12), conveying a spirit of hope for recovery (61), transparency over therapeutic boundaries (72), help to reword abuse accounts to move away from self-blame (23) and making the client feel in control of the pace and depth of the disclosure process (72).

Eleven papers described negative disclosure experiences; contexts included disclosure to family, friends, clergy, health and mental health professionals, including therapists. Participants provided some shocking examples of dismissive, unhelpful and harmful responses. Denial, disbelief or pervasive doubt from the recipients of disclosure were described as destabilising and re-traumatising: this included having descriptions of CSA interpreted as signs of psychosis (14) or in the case of abuse by priests, as acts of blasphemy (22). Several studies described how participants had been silenced and dismissed by family members in response to disclosure attempts in childhood and how the trauma of not being believed in the past had rendered them hypersensitive to even subtle signs of doubt from professionals in the here and now (14,23,37). Within the therapy context, a few participants described how neutral and detached responses from therapists as well as long silences or attempts to control the pace and direction of conversation had made them feel rejected, uncomfortable or as if they were 'on trial' (30,72). Other unhelpful experiences included therapists appearing overwhelmed, ill at ease or inexperienced with discussing CSA (72). Two studies reported men abused by female perpetrators as particularly vulnerable to receiving minimising and trivialising responses to their disclosure (12,56) though men abused by males also recounted experiences of being told to 'get over it' and 'man up' by health professionals (30, 56). Other punitive responses to disclosure included professionals jumping to conclusions about men's sexual orientation or risk of sexual offending (53,56), and loss of control, when partners or friends that men had confided in threatened to tell others against their wishes (23).

Psychological Impact of Disclosure and Non-disclosure

Thirteen papers reported on the psychological impact of CSA disclosure and non-disclosure in adulthood.

Four papers described how for men who had received unsupportive responses, disclosure in adulthood had further exacerbated their sense of powerlessness and despair (12,32,37,72), adding a sense of loss of control over their personal information (14). However, all thirteen papers also reported on the positive, healing and potentially transformative impact of supportive responses to disclosure. They described processes of re-evaluation and personal growth (23,55,61,72). Several papers emphasised the importance of language and story-telling (17,23,33,56): the disclosure process was described as enabling men to heal by putting words to experiences that had previously felt to shameful to be spoken about. Being signposted to survivor networks and support groups was reported to facilitate the process of finding a voice.

Disclosure was described to lead to increased self-understanding by enabling men to 'join the dots' between their CSA experiences and difficulties with substance misuse, intimacy, aggression, trust in relationships, homophobic attitudes or unusual sexual preferences (33). However, greater awareness of problems did not necessarily result in better coping strategies, and participants in three studies described depression or feeling overwhelmed by powerful emotions in aftermath of disclosure (17,33,37).

Four papers reported men voicing regret and a sense of guilt over not disclosing or disclosing with many years delay, blaming themselves for a lack of courage and worrying over whether they could have protected other children by speaking out earlier (23,33,35,55).

Disclosure to partners and family members was described as having the potential to develop more trusting relationships and break longstanding patterns of loneliness and social isolation (17,61). For participants in two studies, disclosure to intimate partners ultimately led to them accessing professional help (19,61).

Conversely, twelve papers outline the negative consequences of continued silence about CSA into adulthood. Participants who had felt unable to disclose their CSA

experience to partners, family or friends described the burden associated with keeping the secret. Men in these studies described a sense of alienation from friends and family, a pervasive sense of fear and paranoia and inability to trust or get close to others (4,14). They reported a sense of lack of control over their lives, loneliness, isolation and a false sense of self. Several papers described the coping strategies by men who had chosen not to disclose as trying to preserve a sense of masculinity by wearing a mask, a façade of toughness and stoicism, rejecting victimhood and taking opportunities to demonstrate macho toughness through driven or risky work and leisure activities. (17,3,53,56,74). Only one study reported positive accounts of the decision not to disclose (33,35): in this study some participants were described as adopting 'defiant narratives' that acknowledged the impact of CSA on their lives but had made a conscious decision not to disclose it as part of their refusal to be defined by the experience.

Discussion

Summary of Findings

This review has summarised and synthesised findings from sixteen qualitative studies examining the experiences of male CSA survivors by reviewing twenty papers based on these study which reported themes of relevance to disclosure in adulthood.

This systematic literature review and meta-synthesis aimed to explore (1) barriers and facilitators to men's disclosure of CSA in adulthood, (2) men's experience of the disclosure process across different contexts and (3) the impact of disclosure and non-disclosure on men's developmental trajectories towards healing, including repercussions for their health, identity and social relationships.

Taken together, the studies included in this review provided rich and detailed information on a broad range of barriers and facilitators to disclosure that were reported by samples of men of different ages, ethnicities and sexualities. The majority of included studies also provided extensive data on the transformative and eventually healing impact of disclosures that received supportive responses and the overwhelmingly negative impact of continued non-disclosure for the participants in these studies. The review was thus able to adequately address aims (1) and (3), though potential limitations regarding the

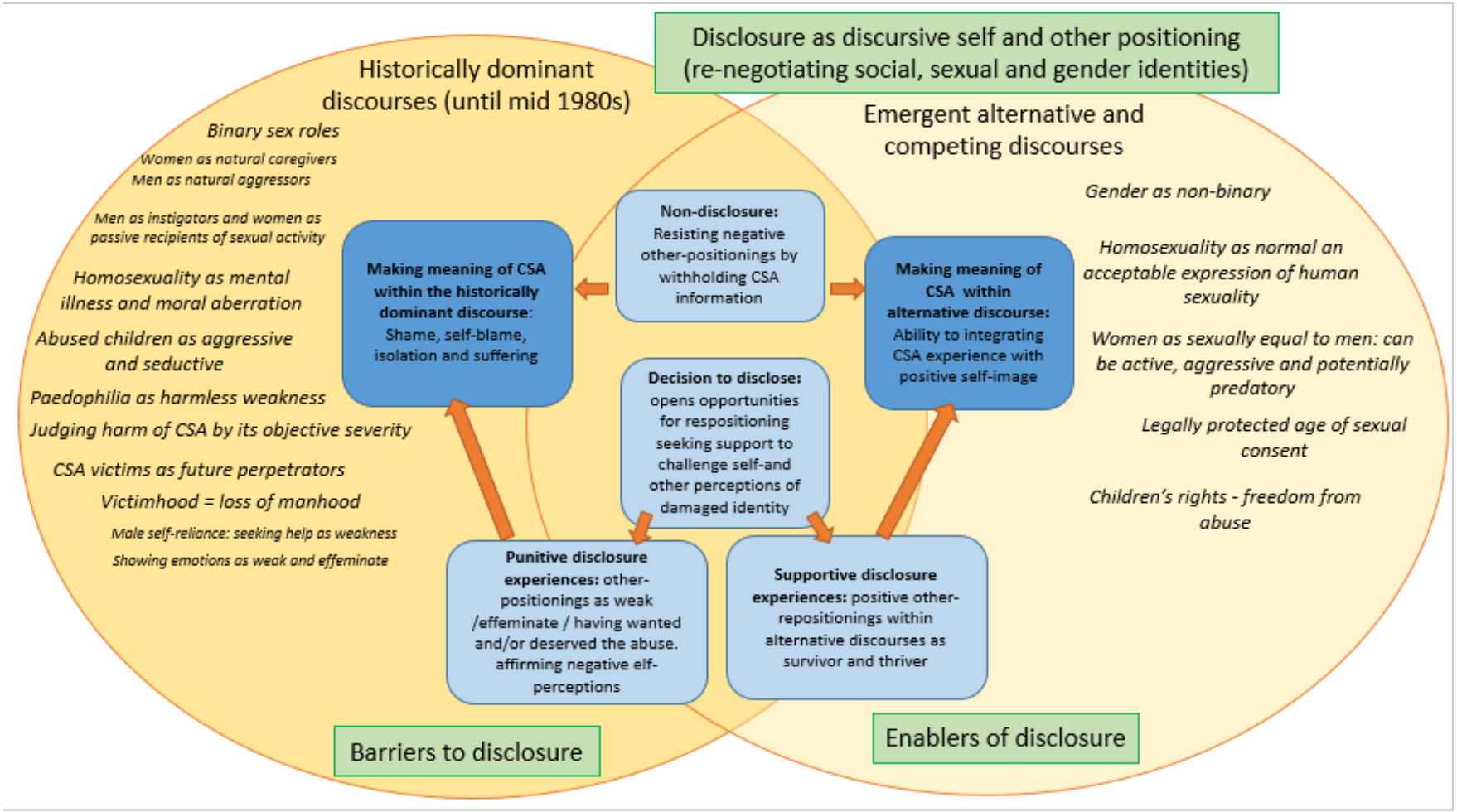
exhaustiveness and generalisability of identified themes arising from selectivity of participant samples are discussed below.

Amongst the included studies, there was a dearth of papers that explored the actual process of CSA disclosure in any depth, and the few studies that provided rich detail and examples of experiential accounts of disclosure were limited to the therapy context. While several studies made reference to men's positive and negative disclosure experiences with partners, friends, work colleagues, health professionals and family members, none of them explored the process, interactional unfolding and relational impact of disclosure in these contexts in any depth. It was therefore not possible to fully address aim (2) of the review.

The range of findings from studies sometimes appeared contradictory at the level of second order themes (e.g. studies reporting same-sex or female perpetrated abuse, institutional or familial abuse as more difficult to disclose; homophobia was mentioned as a barrier to disclosure by both heterosexual and homosexual men). However, it is proposed that these contradictions can be resolved and third-order themes can be integrated into a coherent perspective if we adopt an understanding of men's decisions about and acts of CSA disclosure as discursive positionings (Van Langenhove & Harré, 1993) within a contested space that is characterised by competing discourses on masculinity and generational and gender roles and relationships. This is illustrated in Figure 2.

Within this perspective, disclosure of CSA can be seen as taking place in a contested space between historically dominant and emergent alternative discourses on masculinity, gender roles and sexual equality and diversity. By disclosing CSA in different settings, male survivors take the risk of opening up a space to re-negotiate and challenge previous self- and other understandings about the meanings of the abuse and what it means for their sense of self, social, sexual and gender identities. Supportive responses to disclosure can help male survivors to negotiate more positive identities by challenging the internalised dominant discourse and gradually socialising them into alternative ways of meaning making. Conversely, punitive responses to disclosure can be seen to reaffirm and reinforce the shameful self-positionings afforded by historical discourses.

Figure 2: CSA Disclosure as Discursive Positioning



It is important to note that disclosure may not be an essential requirement for male survivors to contemplate new self-understandings: as suggested by Hunter's study (2009, 2011) some survivors may be able to transform or transcend their CSA experience without sharing their personal CSA experiences. However, all male survivors, whether they choose to disclose or not, need to be able draw on the available competing discourses to be able to challenge the negative and shameful positionings that historically dominant discourses have created for them. Access to role models in the form of other male survivors who have found a voice and access to male-specific CSA resources and services are therefore vital to create a horizon of possibility for men whose self-understandings have become defined and confined by the historically dominant discourse. The literature suggests that many male survivors, once they have achieved alternative self-understandings as survivors and thrivers (Littleton, Buck, Rosman, & Grills-Taquechel, 2012), want to contribute to these emergent discourses and the empowerment of other men with experience of CSA by raising public awareness, promoting male survivor services and finding a voice to speak about what previously was felt to be unspeakable.

Limitations

Pragmatic adaptation of meta-synthesis methods. Due to the small number of papers that examined male CSA disclosure in adulthood as a main topic, a decision was made to include studies examining disclosure alongside other aspects of men's experiences alongside the eight key papers (cf. Wark and Vis, 2016 for a similar approach in this subject area). This meant that at times first order constructs had to be directly translated into third order constructs where second order themes identified by the authors had had no relevance to the theme of disclosure. Coding and translation of second order into third order themes was done by the author and not cross-checked or discussed with a research team as recommended by Noblit and Hare (1988). Instead, a table with examples of first, second and third order themes and how they were translated has been included in the appendix for transparency.

Methodological heterogeneity of included studies. The synthesis draws together study findings carried out within a range of methodological frameworks and ignores

differences in study quality, epistemological and ontological assumptions and in primary data types (interviews, focus groups, written responses). Some scholars have cautioned against synthesising research based on different methodologies (e.g. grounded theory vs. phenomenology) as this might create incongruent results (Florczak, 2013). This review has adopted a pragmatist approach, carefully considering the data within the context of each study's purpose and highlighting how selective sampling and other aspects of study design and focus may have constrained possible findings.

Poor study quality. The synthesis was further limited by the quality of the included papers: only six papers were rated as 'good quality' and three were rated as 'poor'. Poor quality across the sample was apparent particularly in terms of atheoretical study design, overly descriptive analysis, lack of reporting on saturation of themes and lack of consideration of possible bias and limitations. Several papers adopted top-down methods of coding and remained overly descriptive and aggregative in their approach to analysing qualitative data: these studies appeared stuck in a quasi-quantitative paradigm (e.g. reporting percentage of respondents who reported or did not report a particular experience) and failed to make the most of the richness of qualitative data in terms of exploring the factors that were highlighted in participants' own meaning-making of their experiences. It should be noted though that several studies referenced methodological details published elsewhere - poor quality ratings may thus partly reflect tight word limits for publication and, for the seven papers with an explicitly applied focus (12, 72, 20, 30, 61, 56/65), on presenting findings with an emphasis on clinical implications rather than methodological rigour.

Saturation of themes in primary studies. Inadequate data saturation has been identified as a threat to the content validity of primary qualitative research (Fusch & Ness, 2015). Quality appraisal (Table 3) judged only three of the twenty included papers as providing detailed information on the relative saturation of identified themes and eight papers lacked any such information. It was therefore not possible to ascertain to what extent these studies may have reached data saturation for the themes they contributed to the meta-synthesis. Within the qualitative research community, no consensus view seems to have emerged yet as to how poorly saturated themes within primary studies should be treated within meta-synthesis. In contrast to quantitative meta-analysis, qualitative meta-synthesis does not rely on exhaustive inclusion of all available research

finding. Its aims are not aggregation and prediction, but interpretive explanation and conceptual integration of a purposive maximum variation of original studies (Doyle, 2003). The meta-synthesis process privileges 'conceptual saturation' and translation of themes across studies over numerical /aggregative saturation of themes. Thus, several scholars have asserted that the aims of meta-synthesis are unlikely to be compromised by the inclusion of topically relevant but poorly executed or reported individual studies, as long as overall heterogeneity of original samples and settings can be achieved (Dixon-Woods, Sutton, et al., 2007; Thomas & Harden, 2008), just as diversity of participant characteristics and experiences increases chances of data saturation in primary research (Fusch & Ness, 2015). This review has sought to address the issue of saturation with regard to third order themes by including a saturation grid for the initially identified second order themes from primary studies (see appendix, Table A).

Selectivity of participant samples. All but one of the sixteen studies were conducted in Anglo-American countries. There was an overall under-representation of participants from lower socio-economic and BME backgrounds. Twelve of the sixteen studies were based on clinical samples – i.e. men who experienced long-term psychological adverse effects and had accessed therapy. Experiences of male survivors who defined their CSA experience in alternative ways, who either did not disclose or disclosed only to family/ partners but did not access professional help, were under-represented. Findings from this meta-synthesis thus are less likely to be representative of male survivors who have not come into conduct with mental health services, from minority cultures and from lower socio-economic groups.

Directions for Future Research

Most papers explore barriers to adult disclosure and the emotional cost of continued silence, whereas the dialogical process of disclosure and its dynamic unfolding within relationships of power and interdependence was not described in much detail, with the exception of the therapy setting. Given that alongside therapists, partners and family members are prime addressees for men's CSA disclosures in adulthood (Easton, 2013), surprisingly few studies described experiences of disclosure in informal settings, even though repercussions and impact on family and intimate relationships are likely to

be huge, especially for familial abuse. Some researchers have started to examine the systemic impact of male CSA survivors as partners and parents (Jacob & Veach, 2005; Price-Robertson, 2012). Future research should seek to explore men's disclosure experiences in informal settings with a view to establishing support needs in this area, such as facilitation of family communication about CSA and therapeutic post-disclosure support for the family system.

Conclusions

Are We Witnessing Change in Discourses of Masculinity?

In the 1970s, feminist and women's rights movements started to break the silence around female childhood sexual abuse. It has taken around 40 years for similar developments to get off the ground and for society to reach out to male survivors of CSA. A moving instalment of the Oprah Winfrey Show was screened in 2010, when 200 men disclosed their CSA history holding photographs of themselves as boys at the ages when their abuse began. As a society, we are ready and able to recognise young boys as deserving nurture and protection, but somewhere along the way to adulthood, males seem to be denied the recognition that they too can be hurt and violated - and are likely to need help and support from others to cope with and heal from these experiences. There are currently still many more services geared exclusively towards female survivors of CSA than dedicated services for men.

The disclosure of CSA is likely to remain a gendered experience (Sorsoli, Kia-Keating, & Grossman, 2008) for the foreseeable future and both qualitative and quantitative research on male and female experiences of CSA disclosure has consistently found that the gender of the recipient of disclosure – therapists or other service professionals - is an important consideration for many survivors. Whether we need gender-specific CSA survivor services rather than gender-general ones, or whether the issue is better addressed through ensuring that service staff are well-trained, open-minded, compassionate and aware of the diverse needs of CSA survivors is an interesting question for future research.

Can it be hoped that the recent recognition of greater diversity in sexual identities, such as introduction of transgender as a category in its own right, will also have an impact on how we view men who have experienced sexual violence? The idea of a gender continuum goes along with a growing awareness that ideas of masculinity and femininity are socially constructed and limited in their historical reach and validity.

Almost thirty years ago, Finkelhor (quoted in Gill & Tutty, 1999:21) stated *"As a result of dissonances between reality and gender stereotyping, many of the problems experienced by sexually abused males lie in the cognitive realm of beliefs and cultural prescriptions."* It can be speculated whether in the intervening decades, the challenge to binary views of gender through the LGBT community and the emergence of alternative discourses of masculinity in the media and the public domain (see e.g. (McBee, 2014) has opened up a greater array of possibilities for male survivors of CSA to articulate their experiences in ways that allow for the construction of positive identities and self-understandings as strong and manly as well as vulnerable and affected by past injuries at the same time. The findings from this review suggest that overall, many members of past generations sexually abused as boys struggled to break the silence over their distressing experiences, sometimes even in the context of therapeutic support, due to deep-seated shame and self-blame and fears of punitive responses to disclosing the abuse that continued into adulthood. Implications for clinical practice from these findings have been outlined in the hope that future generations of male survivors will come to experience and expect more compassionate and validating responses from mental health services and society at large.

References

Alaggia, R. (2004). Many ways of telling: Expanding conceptualizations of child sexual abuse disclosure. *Child Abuse and Neglect*, 28(11), 1213-1227. doi:10.1016/j.chiabu.2004.03.016

Alaggia, R. (2005). Disclosing the trauma of child sexual abuse: A gender analysis. *Journal of Loss & Trauma*, 10(5), 453-470. doi:10.1080/15325020500193895

Alaggia, R., & Millington, G. (2008). Male child sexual abuse: A phenomenology of betrayal. *Clinical Social Work Journal*, 36(3), 265-275. doi:10.1007/s10615-007-0144-y

BBC News Home. (14th Sept 2010). Catholic Church sex abuse scandals around the world. http://www.bbc.co.uk/news/10407559. Accessed 30th June 2017.

BBC News London. (30 Jan 2017). First male sexual abuse service Clinic26 opens in London. http://www.bbc.co.uk/news/uk-england-london-38797121. Accessed 30th June 2017.

BBC News Northern Ireland. (20 Jan 2017). Northern Ireland child abuse inquiry singles out police and church. https://www.theguardian.com/uk-news/2017/jan/20/northern-ireland-inquiry-report-outlines-shocking-child-abuse. Accessed 30th June 2017.

Briere, J., Evans, D., Runtz, M., & Wall, T. (1988). Symptomatology in men who were molested as children: A comparison study. *American Journal of Orthopsychiatry*, 58(3), 457.

Browne, A., & Finkelhor, D. (1986). Impact of child sexual abuse: a review of the research. *Psychological Bulletin*, 99(1), 66.

Bucholtz, M., & Hall, K. (2005). Identity and interaction: A sociocultural linguistic approach. *Discourse Studies*, 7(4-5), 585-614.

Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M., & Donovan, J. (2003). Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science & Medicine*, 56(4), 671-684.

Deering, R., & Mellor, D. (2011). An exploratory qualitative study of the self-reported impact of female-perpetrated childhood sexual abuse. *Journal of Child Sexual Abuse*, 20(1), 58-76. doi:10.1080/10538712.2011.539964

Denov, M. S. (2003). To a safer place? Victims of sexual abuse by females and their disclosures to professionals. *Child Abuse and Neglect*, 27(1), 47-61. doi:10.1016/S0145-2134(02)00509-4

Der Spiegel. (19th Jul 2010). Die Wurzeln des Missbrauchs [The roots of abuse]. Investigation into male CSA at the Odenwald Private Boarding School between 1960-

1998. https://www.theguardian.com/football/2016/nov/26/football-abuse-scandal-police-warn-allegations-likely-to-spread-to-other-sports. Accessed 30th June 2017.

Dhaliwal, G. K., Gauzas, L., Antonowicz, D. H., & Ross, R. R. (1996). Adult male survivors of childhood sexual abuse: Prevalence, sexual abuse characteristics, and long-term effects. *Clinical Psychology Review*, 16(7), 619-639.

Dixon-Woods, M., Booth, A., & Sutton, A. J. (2007). Synthesizing qualitative research: a review of published reports. *Qualitative Research*, 7(3), 375-422.

Dixon-Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. *Quality and Safety in Health Care*, 13(3), 223-225.

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., . . . Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of Health Services Research & Policy*, 12(1), 42-47.

Dorahy, M. J., & Clearwater, K. (2012). Shame and guilt in men exposed to childhood sexual abuse: A qualitative investigation. *Journal of Child Sexual Abuse*, 21(2), 155-175. doi:10.1080/10538712.2012.659803

Doyle, L. H. (2003). Synthesis through meta-ethnography: paradoxes, enhancements, and possibilities. *Qualitative Research, 3*(3), 321-344.

Draucker, C. B., & Petrovic, K. (1996). Healing of adult male survivors of childhood sexual abuse. *Journal of Nursing Scholarship*, 28(4), 325-330. doi:10.1111/j.1547-5069.1996.tb00382.x

Draucker, C. B., & Petrovic, K. (1997). Therapy with male survivors of sexual abuse: The client perspective. *Issues in Mental Health Nursing*, 18(2), 139-155.

Easton, S. D. (2013). Disclosure of child sexual abuse among adult male survivors. *Clinical Social Work Journal*, 41(4), 344-355.

Easton, S. D., Leone-Sheehan, D. M., Sophis, E. J., & Willis, D. G. (2015). "From that moment on my life changed": Turning points in the healing process for men recovering from child sexual abuse. *Journal of Child Sexual Abuse*, 24(2), 152-173.

Easton, S. D., Saltzman, L. Y., & Willis, D. G. (2014). Would you tell under circumstances like that?": Barriers to disclosure of child sexual abuse for men. Psychology of Men & Masculinity, 15(4), 460-469.

Etherington, K. (1997). Maternal sexual abuse of males. *Child Abuse Review*, 6(2), 107-117.

Fater, K., & Mullaney, J. A. (2000). The lived experience of adult male survivors who allege childhood sexual abuse by clergy. *Issues in Mental Health Nursing*, 21(3), 281-295. doi:10.1080/016128400248095

Finkelhor, D. (1988). The Trauma of Child Sexual Abuse: Two Models.[In:] G. Wyatt, G. Powell (ed.) *Lasting Effects of Child Sexual Abuse* (pp. 61-82): London: Sage.

Finkelhor, D., Hotaling, G., Lewis, I. A., & Smith, C. (1990). Sexual abuse in a national survey of adult men and women: Prevalence, characteristics, and risk factors. *Child Abuse & Neglect*, 14(1), 19-28.

Florczak, K. L. (2013). In the zeal to synthesize: A call for congruency. *Nursing Science Quarterly*, 26(3), 220-225.

Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report, 20*(9), 1408.

Gagnier, C., & Collin-Vézina, D. (2016). The disclosure experiences of male child sexual abuse survivors. *Journal of Child Sexual Abuse*, Survivors, & Offenders, 25(2), 221-241. doi:10.1080/10538712.2016.1124308

Gill, M., & Tutty, L. M. (1999). Male survivors of childhood sexual abuse: A qualitative study and issues for clinical consideration. *Journal of Child Sexual Abuse*, 7(3), 19-33. doi:10.1300/J070v07n03_02

Holmes, W. C., & Slap, G. B. (1998). Sexual abuse of boys: Definition, prevalence, correlates, sequelae, and management. *JAMA*, 280(21), 1855-1862.

Hovey, A., Stalker, C. A., Schachter, C. L., Teram, E., & Lasiuk, G. (2011). Practical ways psychotherapy can support physical healthcare experiences for male survivors of childhood sexual abuse. *Journal of Child Sexual Abuse*, 20(1), 37-57. doi:10.

Hunter, S. V. (2009). Beyond surviving: Gender differences in response to early sexual experiences with adults. *Journal of Family Issues*, 30(3), 391-412. doi:10.1177/0192513X08321493

Hunter, S. V. (2010). Evolving narratives about childhood sexual abuse: Challenging the dominance of the victim and survivor paradigm. *Australian and New Zealand Journal of Family Therapy*, 31(2), 176-190. doi:10.1375/anft.31.2.176

Hunter, S. V. (2011). Disclosure of child sexual abuse as a life-long process: Implications for health professionals. *Australian and New Zealand Journal of Family Therapy*, 32(2), 159-172. doi:10.1375/anft.32.2.159

Isely, P. J., Isely, P., Freiburger, J., & McMackin, R. (2008). In their own voices: A qualitative study of men abused as children by catholic clergy. *Journal of Child Sexual Abuse*, 17(3-4), 201-215. doi:10.1080/10538710802329668

Jacob, C. M. A., & Veach, P. M. (2005). Intrapersonal and familial effects of child sexual abuse on female partners of male survivors. *Journal of Counseling Psychology*, 52(3), 284.

Katrak, P., Bialocerkowski, A. E., Massy-Westropp, N., Kumar, V. S., & Grimmer, K. A. (2004). A systematic review of the content of critical appraisal tools. *BMC Medical Research Methodology*, 4(1), 22.

Kia-Keating, M., Grossman, F. K., Sorsoli, L., & Epstein, M. (2005). Containing and Resisting Masculinity: Narratives of Renegotiation Among Resilient Male Survivors of Childhood Sexual Abuse. *Psychology of Men & Masculinity*, 6(3), 169.

Lisak, D. (1995). Integrating a critique of gender in the treatment of male survivors of childhood abuse. *Psychotherapy: Theory, Research, Practice, Training,* 32(2), 258.

Littleton, H., Buck, K., Rosman, L., & Grills-Taquechel, A. (2012). From survivor to thriver: a pilot study of an online program for rape victims. *Cognitive and Behavioral Practice*, 19(2), 315-327.

McBee, T. (2014). *Man Alive: A True Story of Violence, Forgiveness and Becoming a Man.* Edinburgh: Canongate Books Ltd.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies* (Vol. 11): Sage.

O'Leary, P. J., & Gould, N. (2010). Exploring coping factors amongst men who were sexually abused in childhood. British journal of social work, 40(8), 2669-2686. doi:10.1093/bjsw/bcq098

O'Leary, P., & Gould, N. (2008). Men who were sexually abused in childhood and subsequent suicidal ideation: Community comparison, explanations and practice implications. *British Journal of Social Work*, 39(5), 950-968.

O'Leary, P., Coohey, C., & Easton, S. D. (2010). The effect of severe child sexual abuse and disclosure on mental health during adulthood. *Journal of Child Sexual Abuse*, 19(3), 275-289. doi:10.1080/10538711003781251

Price-Robertson, R. (2012). Child sexual abuse, masculinity and fatherhood. *Journal of Family Studies*, 18(2-3), 130-142.

Radford, L., Corral, S., Bradley, C., Fisher, H., Bassett, C., Howat, N., & Collishaw, S. (2010). Child abuse and neglect in the UK today. NSPCC: London. Retrieved from https://www.nspcc.org.uk/globalassets/documents/research-reports/child-abuse-neglect-uk-today-research-report.pdf. Accessed 30th June 2017:

Reitsema, A., & Grietens, H. (2016). Is anybody listening? The literature on the dialogical process of child sexual abuse disclosure reviewed. *Trauma, Violence, & Abuse*, 17(3), 330-340.

Shotter, J. E., & Gergen, K. J. (1989). *Texts of identity*. London: Sage

Sigurdardottir, S., Halldorsdottir, S., & Bender, S. S. (2012). Deep and almost unbearable suffering: Consequences of childhood sexual abuse for men's health and well-being. *Scandinavian Journal of Caring Sciences*, 26(4), 688-697. doi:10.1111/j.1471-6712.2012.00981.x

Sigurdardottir, S., Halldorsdottir, S., & Bender, S. S. (2014). Consequences of childhood sexual abuse for health and well-being: Gender similarities and differences. *Scandinavian Journal of Public Health*, 42(3), 278-286. doi:10.1177/1403494813514645

Sorsoli, L., Kia-Keating, M., & Grossman, F. K. (2008). "I keep that hush-hush": Male survivors of sexual abuse and the challenges of disclosure. *Journal of Counseling Psychology*, 55(3), 333-345. doi:10.1037/0022-0167.55.3.333

Stoltenborgh, M., Van Ijzendoorn, M. H., Euser, E. M., & Bakermans-Kranenburg, M. J. (2011). A global perspective on child sexual abuse: Meta-analysis of prevalence around the world. *Child Maltreatment*, 16(2), 79-101.

Teram, E., Stalker, C., Hovey, A., Schachter, C., & Lasiuk, G. (2006). Towards malecentric communication: Sensitizing health professionals to the realities of male childhood sexual abuse survivors. *Issues in Mental Health Nursing*, 27(5), 499-517. doi:10.1080/01612840600599994

The Guardian. (26th Nov 2016). Football abuse scandal: police warn allegations likely to spread to other sports. https://www.theguardian.com/football/2016/nov/26/football-abuse-scandal-police-warn-allegations-likely-to-spread-to-other-sports. Accessed 30th June 2017.

Third Force News. (26 May 2017). Support for male sexual abuse survivor charities. http://thirdforcenews.org.uk/tfn-news/support-for-male-sexual-abuse-survivor-charities#TwyvYzls2MmtfxMD.99. Accessed 30th June 2017.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology, 8*(1), 45.

Van Langenhove, L., & Harre, R. (1993). Positioning and autobiography: Telling your life. In N. Coupland & J. F. Nussbaum (Eds.), *Discourse and lifespan identity* (pp. 81-99). London: Sage.

Walsh, D., & Downe, S. (2005). Meta-synthesis method for qualitative research: a literature review. *Journal of Advanced Nursing*, 50(2), 204-211.

Washington, P. A. (1999). Second assault of male survivors of sexual violence. *Journal of Interpersonal Violence*, 14(7), 713-730.

Appendix for Literature Review

Target Journal Information

Description of the Three-Stage Searching and Screening Process

Stage 1: Systematic searching of databases

Rationale for Design of the Search String

Table of Databases Included in the Search Process

Stage 2: Screening of abstracts

Table of Inclusion and Exclusion Criteria for First Round Screening of Abstracts

Stage 3: Second Round Screening of Full-text Papers

Table with Criteria for Second Round Screening of Full-Text Papers

Quality Appraisal Checklist

Table A: **Saturation of Themes Across the Sample of Included Studies**

Table B: Examples of First, Second and Third-Order Themes

Target Journal Information

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Rationale for Design of the Search String

Childhood sexual abuse is a topic associated with societal taboo, secrecy, stigma and shame for those who have experienced it. Perceptions and experiences relating to disclosure and non-disclosure are therefore likely to feature prominently in the accounts of CSA survivors. As the qualitative literature on the experience of male CSA survivors is still relatively small, it was decided not to specify the topic of disclosure in the search string, so as not to inadvertently exclude studies that did not identify disclosure as the main focus of study, but might nevertheless include themes relevant to disclosure as part of their analysis.

The search string therefore only specified participants (synonyms of men), topic area (childhood sexual abuse) and methods (qualitative research) and after initial piloting was operationalised as follows: *((male OR men) AND (survivor* OR victim* OR adult*) AND child* AND sex* AND abuse* AND (qualitative OR interview*))*, to be searched for in abstracts, titles and keywords.

Table of Databases Included in the Search Process

This table describes lists the databases that were searched using the search string, their scope, number of hits and additional notes on how the search was executed.

Database	Scope	Notes	Number of hits
APA Psych Net	searches across PsycINFO (articles, books and dissertations), PsycEXTRA (grey literature), PsycTESTS (tests and measures) and PsycARTICLES PsychInfo.	Filtered by index terms: Child abuse, sexual abuse and filtered by publication type: peer-reviewed journal:	144
Scopus	The world's largest abstracts and citations database of peer-reviewed journals, searching across health, life, physical, social sciences, engineering and humanities.	Limiters set to publication type: journal articles and reviews and to Keyword: child abuse, sexual	365
IBSS	International Bibliography of the Social Sciences - database covering social science books and journals.	n/a	22
PubMed	Free version of Medline which indexes journal articles for medicine, nursing the healthcare system and preclinical sciences.	n/a	219
Social Policy and Practice	Simultaneously searches databases including AgeInfo, ChildData and Soci al Care Online: a large proportion of its references relate to grey literature e.g. reports, legislation, local/national government documents, organisations, policies, press coverage and service user knowledge - the focus is on applied research & practice.	n/a	78
Web of Science	Core collection: includes a wide variety of topics.	n/a	489

Description of the Three-Stage Searching and Screening Process

Stage 1: Systematic searching of databases

Endnote reference software version 8 and QSR Nvivo software version 11 were used to assist the screening process.

Citations from the six searched databases (Table xxx) were downloaded with titles and abstracts into separate endnote databases. References were then merged into a single database and duplicate references were removed. This resulted in a list of 910 abstracts references for screening.

Stage 2: Screening of abstracts

Abstracts were screened independently by two researchers (KB and LF) according to first round screening criteria as specified in Table 2. Each references was scrutinised using the following series of screening questions:

Does the study report on contact sexual abuse (i.e. involving bodily contact between victim and perpetrator as opposed to e.g. indecent images)? No => exclude; Yes or unable to tell=> continue.

Did the abuse occur in childhood (i.e. before age 18)? No => exclude; Yes or unable to tell=> continue.

Is it a qualitative study? No => exclude; Yes or unable to tell => continue.

Does the sample include adult men abused as children as interview participants?

No=> exclude; Yes or unable to tell

=> mark as INCLUDE if all 5 criteria are 'yes', or as 'retrieve to decide' if at least one criterion is 'unable to tell'.

The table below provides an overview of the criteria for including and excluding papers and for or deferring the decision until a full text could be retrieved.

Table of Inclusion and Exclusion Criteria for First Round Screening of Abstracts

	Inclusion criteria	Retrieve to decide	Exclusion criteria
Type of publication	Peer reviewed publication	Unclear whether publication is peer-reviewed	Grey literature (e.g. project reports, unpublished theses, books or book chapters or opinion pieces (e.g. journal editorial)
Type of abuse	Study reports on contact sexual abuse	Study does not have an abstract (unless title is clearly not about men as victims of abuse)	Not about contact sexual abuse
Time of abuse	Sexual abuse occurred in childhood (i.e. victim <18 years old)	Unclear whether referring to abuse in childhood or adulthood	Sexual abuse occurred in adulthood OR Not about men as victims of abuse (i.e. study with perpetrators as informants)
Method	Qualitative methodology (i.e. based on interviews or focus groups with informants) OR mixed methods study including use of qualitative methodology as described above	Study does not specify methodology	Methodology not qualitative (i.e. findings not based on qualitative analysis of interviews or focus groups): if too little detail to judge, mark as 'retrieve to decide' Single case studies of abuse survivors
Participants	Informants are adult male CSA survivors OR Informants are a mixed sample which includes adult male CSA survivors (e.g. male and female, adult & adolescent men, male survivors and professionals)	Study does not specify gender or age of informants OR it is unclear from abstract whether male CSA survivors constitute a clearly defined subgroup of participants	Female only sample OR sample of family members or health professionals working with male survivors OR single case study of male survivor OR experience of CSA is a finding of the study and not a criterion for participant recruitment (e.g. study of HIV positive men, some of whom were found to experience CSA

Agreement between raters for first round screening of abstracts to identify references for which to retrieve full-text papers was 94.76%. In case of disagreement between raters, full-text versions were retrieved. A total of 76 full text papers were retried.

Stage 3: Second Round Screening of Full-text Papers

Following Dixon-Woods et al. (2007), screening of full-text papers resulted in each paper being assigned to one of four categories:

Included papers (N=20):

1. **Key Paper (KP, N=8)):** if disclosure of CSA in adulthood is main focus of paper AND male survivors are either the only group or a clearly identified subgroup of participants.
2. **Satisfactory paper (SAT, N=15)**: if disclosure of CSA in adulthood is covered as one of the themes of analysis AND male survivors are either the only group or a clearly identified subgroup of participants.

Excluded papers (N=56):

3. **Fatally flawed paper (FF, N=38):** means fatally flawed for the purpose of this review, i.e. findings for male survivors not reported separately AND/OR methods of analysis not qualitative.
4. **Irrelevant paper (IRR, N=18):** paper meets inclusion criteria but focus of paper and reported findings are not relating to disclosure of CSA in adulthood

20% of full-text papers were double-coded by a second rater with experience in qualitative research methods (LF-yet to be done!). The Table below summarises the screening criteria for full-text papers.

Table with Criteria for Second Round Screening of Full-Text Papers

	Inclusion criteria	**Exclusion criteria**
Topic- relevance to research question	Disclosure of CSA in adulthood is the main focus of the paper **(mark as key paper, KP)** **OR** Disclosure in adulthood is one of the themes identified in the analysis **(mark as relevant paper, RP)**	Does not cover disclosure as a theme **OR** Only covers disclosure of abuse in childhood not adulthood **OR** Conceptual paper not based on analysis of empirical data **(Mark as irrelevant paper, IRR)**
AND		OR
Participants Was experience of CSA a selection criterion for recruiting (a distinct subgroup of) participants?	Sample includes only male CSA survivors OR Mixed sample but findings for male CSA survivors reported separately (e.g. sample includes men and women but focuses on gender differences)	Disclosure in adulthood is a theme but participants are a mixed sample and findings for male CSA survivors not reported separately (e.g. sample of male perpetrators some of whom were abused in childhood, or sample of adults who experienced sexual violence but not clear at what age) **(Mark as Fatally flawed paper, FF)**
AND		OR
Method of analysis and reporting of findings	Qualitative analysis of data (i.e. analysis is based on transcripts of audio-recorded interviews or focus groups with participants or their written responses to narrative questionnaires) and ***findings are illustrated with verbatim quotes from participants***	Disclosure in adulthood is a theme and findings for men are reported separately and data are interviews or focus group but method of analysis is not qualitative (e.g. content analysis or coding for the purpose of doing frequency counts, descriptive statistics) **Mark as Fatally flawed paper, FF)**

Quality Appraisal Checklist

Purpose

This list aims to provide a rough instrument to assess the quality of study reporting, study design and study execution of the included papers. Quality ratings based on this list are provided for all included papers in Table 3 in the main text. Study findings have been considered as part of the synthesis even if they originated from studies with low quality scores. However, the quality rating has been taken into account in the relative weight assigned to findings.

Please rate each criterion as either good=2; satisfactory=1; poor or absent=0

Recruitment and Data collection (max. 8 points)

- ☐ Description of a methodological framework for the study (e.g. grounded theory)
- ☐ Description of methods of participant recruitment (e.g. self-selected, through therapists)
- ☐ Description of participant demographics (age, gender etc)
- ☐ Description of methods of data collection (e.g. who did the interviews, what questions were asked, audio-recorded? Transcribed verbatim?)

Data Analysis (max. 8 points)

- ☐ Description of methods of data analysis (e.g. linked to a framework? Description of the process)
- ☐ Use of measures to increase validity and reliability of data analysis (e.g. use of analysis software, second coder, themes discussed in team, etc.)
- ☐ Provision of verbatim quotes to illustrate themes from a range of study participants
- ☐ Analysis provides information regarding the saturation of themes (i.e. is this a repeated theme across participants or a one-off mention?)

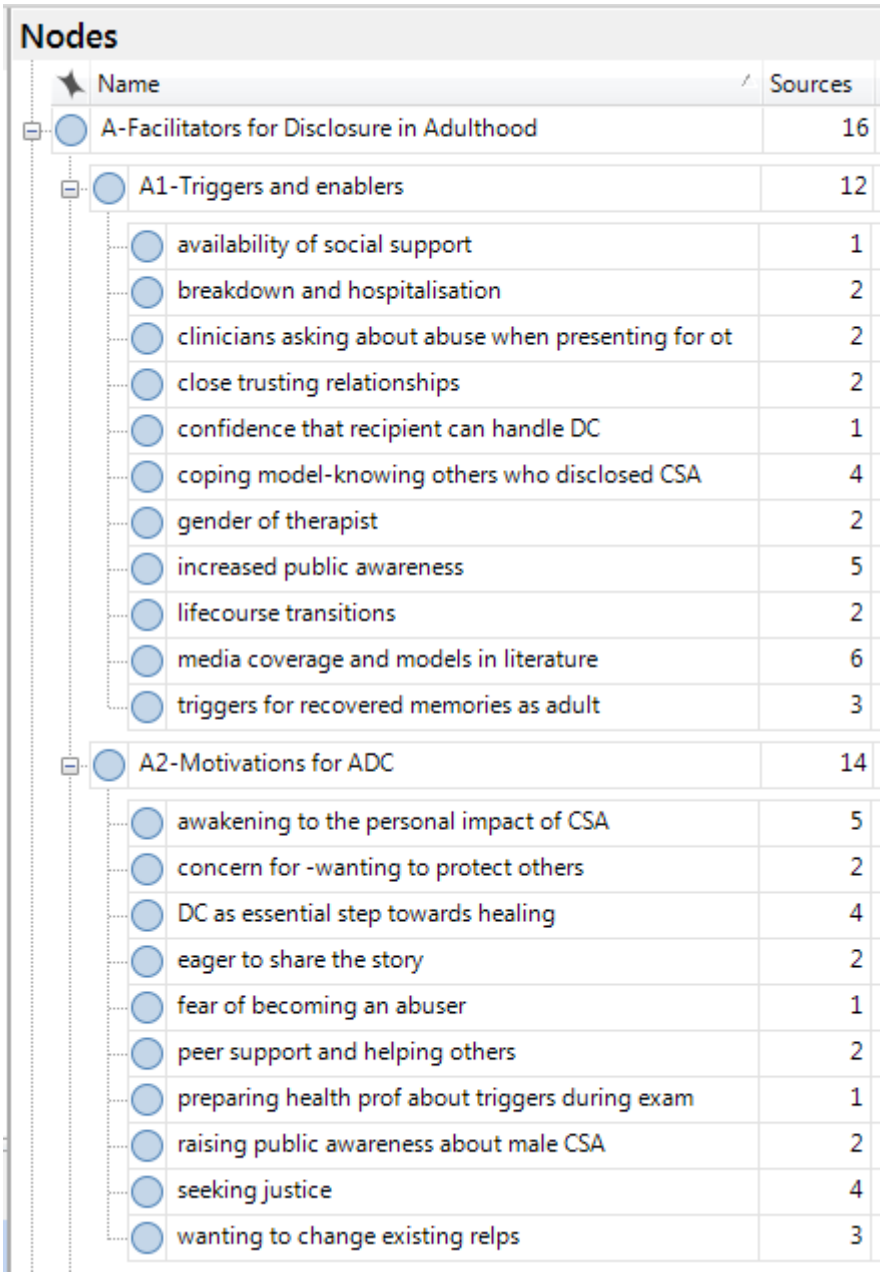
Conceptual integration (max. 6 points)

- ☐ Interpretations are grounded in the empirical data (i.e. not overly speculative or just the expert opinion of the authors)
- ☐ Authors consider possible biases and limitations of their methods and how they may have impacted on the generated data (e.g. arising from selective recruitment, focus of questions asked)
- ☐ Paper provides a conceptual integration of identified themes (e.g. linking back to theories and/or previous findings from previous research)

Total Score ___ of 22 points

Table A: Saturation of Themes Across the Sample of Included Studies (N=16)

Screenshots from QSR Nivvo Qualitative Analysis Software, showing the number of sources (studies) that contributed to the identified themes across studies. Themes listed in the tables below were initially closely reflected the labelling of second order themes in the original studies but were further regrouped and, where possible, synthesised into third order themes (see Table B) for presentation in the written results section.



Nodes

Name	Sources
A-Facilitators for Disclosure in Adulthood	16
A1-Triggers and enablers	12
availability of social support	1
breakdown and hospitalisation	2
clinicians asking about abuse when presenting for ot	2
close trusting relationships	2
confidence that recipient can handle DC	1
coping model-knowing others who disclosed CSA	4
gender of therapist	2
increased public awareness	5
lifecourse transitions	2
media coverage and models in literature	6
triggers for recovered memories as adult	3
A2-Motivations for ADC	14
awakening to the personal impact of CSA	5
concern for -wanting to protect others	2
DC as essential step towards healing	4
eager to share the story	2
fear of becoming an abuser	1
peer support and helping others	2
preparing health prof about triggers during exam	1
raising public awareness about male CSA	2
seeking justice	4
wanting to change existing relps	3

Nodes

Name	Sources
B-Barriers to ADC	16
being silenced and fear of reprisal	2
belief it's not affected me	2
concern over confidentiality	2
denial-represssion-lack of awareness	14
dissociation-cutting off	4
failure to recognise CSA	5
fear of being blamed for the abuse	3
fear of being judged as damaged beyond repair	2
fear of being perceived as potential abuser	7
fear of being seen as weak victim not man enough	8
fear of being stereotyped-judged	6
fear of damaging existing relationship	2
fear of homophobia - being labelled homosexual	10
fear of not being believed	4
fear of not being taken seriously	2
fear of unleashing uncontrollable emotions	1
feels like breaking a cultural taboo	7
fragmented vague memories-doubt about abuse being	3
habit-learned behaviour	3
hard to hear for others	2
lack of language and emotional literacy	1
lack of public awareness and male-specific services	5
needing to forget-resisting the pressure to tell	3
not feeling ready or safe enough to tell	3
refusing be defined by CSA	1
resilience-no need	1
sense that telling won't change things	1
shame and self-blame - feeling complicit	12
uncertain how to approach	4
uncertainty over consequences and others reactions	5
uncertainty-shame over own sexuality-male perp	2
unsupportive response to previous DC attempts	3
violation of cultural-ethnic norms	7
wanting to move on	2
wanting to protect family members	4

Nodes

Name	Sources
C-Experience of ADC	8
C1-Adult disclosure context	17
church or clergy	1
family members	5
first ADC-to whom	7
friends	4
going public on TV	1
law enforcement	3
mental health context	2
partners	7
physical health	4
psychotherapy	7
research only	3
selfhelp groups	2
C2-positive response to -experience of ADC	4
being believed	2
importance of hope	1
support and empathy	1
transparency and pacing-control of process	1
validation	2
C3-negative response to-experience of ADC	11
being silenced	3
disbelief and denial	3
invalidation -lack of empathy	1
presumptions made about sexual orientation	1
professional minimisation and denial	3
punitive response to ADC	4
reframing female CSA as desirable experience	4
ridicule	0
therapist overwhelmed	1
told to man up	2
experience of telling	3
importance of hope	1
support and empathy	1
transparency and pacing-control of process	1
validation	2

Nodes

Name	Sources
C-Experience of ADC	8
C1-Adult disclosure contexts	16
C2-positive response to -experience of ADC	4
being believed	2
importance of hope	1
support and empathy	1
transparency and pacing-control of process	1
validation	2
C3-negative response to-experience of ADC	11
being silenced	3
disbelief and denial	3
invalidation -lack of empathy	1
presumptions made about sexual orientation	1
professional minimisation and denial	3
punitive response to ADC	4
reframing female CSA as desirable experience	4
ridicule	0
therapist overwhelmed	1
told to man up	2
experience of telling	3
importance of hope	1
support and empathy	1
transparency and pacing-control of process	1
validation	2

Nodes

Name	Sources
D-impact of ADC	13
DC to self-making connections to difficulties	1
further victimisation and powerlessness	4
gaining a more nuanced understanding	1
healing and sense of self-efficacy	1
impact of ADC on well-being	5
impact of DC on identity	6
impact of DC on relationships	3
lack of control-uncertain consequences	2
personal growth-victim to survivor	3
referral for prof help	2
reframing and normalising	1
return to denial and avoidance	2
unleashing powerful emotions	1
E-Impact of Non-disclosure	12
false self and secrecy	3
isolation and emotional distance	6
preserving a sense of masculinity	1
regret and guilt about non-disclosure	4
relationship problems to do with sex and intimacy	6

Table B: Examples of First, Second and Third-Order Themes

Third Order Constructs	Second-Order Constructs	First-Order Constructs
Barriers to disclosure		
Denial / lack of awareness / failure to recognise experiences as abuse	Fragmented, vague or repressed memories	*"I simply did not remember the abuse until my perp died"*
	Pervasive doubt	*"I've found that very difficult [to fully accept my abuse history]. Did this really happen or didn't it? I get that sort of doubt in my mind, did it happen? Well of course it happened. I don't know why the doubt keeps creeping back when...the abuser actually came and told me it happened. And I thought, that's confirmation enough but I still don't completely believe it."*
	Making sense of the abuse in alternative ways	
	Belief that 'it has not affected me'	*"Abuse is a word used for both beating and physical assault and for sexual activity and in my case there was no question of assault of any kind. Sexual abuse now carries overtones of wickedness, prison and that kind of thing and I don't like applying that, for example, to my mother."*
		Bert (who had sexual experiences with an older man at the age of 11) described his choice not to talk to friends about what happened: "The reason that I haven't discussed it, I think, is that I'm afraid of their reaction, because I don't think that I've been traumatized by this event."
Shame and self-blame	Confusion around complicity in abuse	*"I wanted it. I mean I stayed there. I let it happen, it felt good. I mean although something told me it was wrong and, you know, when I ejaculated it felt great. But then after I'd feel, like, sick to my stomach.''*
	Conflicted feelings	

	Social stigma – fear of being judged by others	*"And even though it's fractured, I do have some memories of going back to my father ... and I feel horrible about that but I understand also that he loved me. I mean it was this affection time."*
	Experiences to shameful to articulate	*Amhad also referred to the ways disclosure felt shameful. He added that he wanted to minimize the experience, "make it less," or just not say the words that described what had really happened.*
		"What normal male wants to tell others that he was abused by an old man, a teacher, or a priest?"
		"It's more difficult for me to talk about the [female perpetrated] incest than the incest by my father. It was really hard to come forward and say that I was sexually abused by a woman. Those were hard times for me"
Not wanting to be defined by CSA experience	Homophobia / Fear of being thought homosexual	*"My biggest fear was being seen as gay...that was one of my biggest fears about talking about it."*
	Fear of being seen as unmanly /effeminate	
	Fear of being judged/stereotyped	*"I was a very thin child with very curly light brown hair and I was called a f—–, a girl, um, a sissy, um... . And that just destroyed myself, my sense of self, just I mean brutal [trails off]." He further explained that for him to have disclosed sexual abuse would have meant to be further characterized by this undesirable trait of being a victim and feminine-like.*
	Narratives of defiance	
	Fear of others making assumptions about (origins of) sexual orientation or preferences	
	Loss of control over personal information	
	feared impact on identity as 'damaged goods'	*"Men don't want to talk about these things, 'cause we're already in a society where it's easy for us to be accused as rapists or violators."*

		"In my day [men were] taught to be tough … don't show emotions … that kind of thing, right, that's only for weaklings, and, and fairies or whatever."
Violation of cultural norms	Protecting others from their lack of understanding	"If they knew I was sexually abused, they may think that I will sexually abuse their children."
	Homophobia	*"Sexual abuse, especially between a male perpetrator and male victim is problematic... because it tends to be a societal statement about a person's manhood and sexual orientation. That is, gay sex=bad. Abuse=bad. Gay abuse=really bad. I think many men who were abused by men assume that people will think that they are gay even when they are not."*
	Female-perpetrated abuse as ultimate taboo subject	*"The reaction of professionals when I would talk about the sexual abuse by my mother was 'we don't want to hear about that.' I would be shut down. I was told I was 'changing the subject' and told 'just how bad could that have been?' These were horrible experiences. I went to different groups, but I would get the same reaction".*
Fear of unsupportive, judgmental or punitive response	View of female-perpetrated abuse as trivial /not harmful	*"Who are you going to report female abuse to? The police? They laugh at you. I've had that happen … . There's nobody you can turn to"*
	Previous experience of punitive responses and victim-blaming	*Told to 'man up'*
Uncertainty and fears over social and personal	Silence can feel safer	*I would be very careful about telling anyone; in all but two cases (therapist and second wife) it came back to haunt me.*
	Fear of unsettling existing relationships	

consequences of disclosure	Fear of reprisals	*'My parents are still alive. They're in their nineties you know. And I wouldn't want to create any hurt by raising the issue at this late stage of their lives.'*
	Fear of loss of control over information	*"I think that these things happened to us and it would be good if we could talk freely about how shit our childhood was. But there are also concerns, I have concerns about whether [others are] in the right space, or I'm in the right space to talk about that. What the appropriate forum is, it's like everyone's dealing with their own little bit of it but none of that's integrated."*
	Unleashing powerful emotions of grief and anger avoided for years	
Lack of public awareness	lack of CSA services for men	*"Society has gone to great lengths to get the issue of women's abuse out of the closet, and out in to the open. The notion that men can be victims has unfortunately not evolved in the same way. In my early explorations about possibly seeking help I can't tell you how many sexual assault centers simply do not provide services to men with historical abuse"*
Facilitators to disclosure		
(a) Triggers and enablers	Experience of flashbacks after ceasing substance misuse	*"My first experience with alcohol was that, boy, I didn't have to remember anything ugly… I had now been dealing with all my memories of my childhood that had been flooding in from the understanding that this is not normal. Umm, all of a sudden [in recovery] I was flooded with information that I had blocked out."*
	Recovered memories	
		"I drank heavily for many years to

		keep the memories suppressed. When I decided to get sober, the memories came back and I realized that I would never maintain sobriety unless I dealt with the abuse."
Recognising experience as abuse	Cognitive realisation	
	Shift in meaning-making	
	Role models in media or literature	
	Presenting in therapy for other problems	*"When I first started to disclose, I had just (pause)… at 37, my wife had left me. I had a major breakdown. I was a drug addict and alcoholic at the time.''*
	Hospitalisation	
	Breakdown and crises	*What stopped them from committing suicide was revealing to others what happened to them. They were at rock bottom when they stood on the precipice and told someone of their experiences and held onto life.*
Availability of Social Support	Familial and structural factors	*"In the last seven years things have changed. I gave up drugs. In the light of the truth of what actually happened, I was helped to see it wasn't my fault. It happened when a guy raped my niece and she confided in me, it all came flooding back to me, and I got help. I wasn't alone."*
	Access to support groups and networks	
Experience of /access to others speaking out	Media reports of CSA	*"On the way home from the therapist, I heard [a] breaking story on NPR about the scandal in the Boston Archdiocese. For the first time, I knew I was not alone. This was the turning point"*
	Examples in literature	
	Receiving abuse disclosures from others	*"I had decided to keep quiet until my mother came and sat with me and told me "it also happened to me"… it hadn't just happened to me … then I knew that since she understood what I had*

		experienced, I could tell her my story."
	Personal knowledge of other CSA survivors	*"The fact that my friend … had also been a victim, and that three of her ex-boyfriends, guys [also had been abused], it sort of authorized me to talk about it."*
	Increased Public Awareness	
(b) Motivations	Disclosure seen as essential step towards healing	
	Breaking the silence	
	Finding a voice	
	Making links with other – recognition "I'm not alone"	
Wanting to change existing relationships	Referral for couple counselling / threat of marital break-up	
	Seeking validation from	
	Confronting the perpetrator	
Wanting to protect others	Advocacy and raising publicity	*''And then you know I said even though I seem well adjusted I just didn't want things coming back from my past to haunt me and you know. My kids were actually the biggest fear. That was my biggest fear, sexually abusing my girls.'' Another participant described it this way: ''What scared me is am I capable of doing what my father did to me? Am I capable of doing what my uncles did?''*
	Becoming a parent	
	Pursuing legal action	
	Fear of becoming an abuser	
Experiences of disclosure		
(a) Qualities of helpful responses	Validation	*"To validate that experience because you don't know how much you've been there, how hard it is to keep that buried for 20 years and then bring it out and start talking*

	Supportive, calm and unfazed listening	*about it and then look across and see a look of what you might perceive to be disbelief in somebody's eyes and you're wondering inside yourself, you know about, maybe I am crazy and it didn't really happen or it wasn't like that or, you're supposed to be a man and it wasn't that bad and just shake it off and carry on."*
	Abuse treated seriously	
	Healing	
	Sign-posting to support	*"[The second professional] took the sexual abuse by my mother very seriously. He said my mother acted completely inappropriately. I had never heard [a professional] say that ... I felt such a sense of relief. It reinforced that what I was feeling was real"*
	Instilling hope for the future	
		"I was very close to killing myself. The police officer was wonderful and understanding. I told her everything. She gave me my current therapists' number"
		"The main thing that helped was talking about it [the sexual abuse] and knowing that I was believed. He [the counsellor] gave me hope that I can overcome the cards that have been dealt to me, and become something I want to become."
(b) Qualities of unsupportive responses	Trivialising /ridicule over of female-perpetrated abuse	*"Well no, they're not saying, "I don't believe you." Some of them will say to you, "Well you know—sexual experimenting." And I told them, "Well look, I was sexually abused by someone who was 18 years old approximately, and I was about 11. There's no sexual experimentation there, not on my part. I was abused. I wasn't experimenting. I didn't even know what the hell sex was."*
	controlling, manipulative and intrusive therapists	
	inexperienced and overwhelmed therapists	

	Being dismissed, silenced, rejected and judged	*"I [told] my therapist: 'my mother fellated me in the bathtub.' I got really emotional. [He] tried to change the subject. He was obviously very nervous about it. He didn't want to hear about abuse by a woman".*
	Punitive and threatening responses	*"The reaction of professionals when I would talk about the sexual abuse by my mother was 'we don't want to hear about that.' I would be shut down. I was told I was 'changing the subject' and told 'just how bad could that have been?' These were horrible experiences. I went to different groups, but I would get the same reaction."*
		"*The reaction of professionals when I would talk about the sexual abuse by my mother was 'we don't want to hear about that.' I would be shut down. I was told I was 'changing the subject' and told 'just how bad could that have been?' These were horrible experiences. I went to different groups, but I would get the same reaction*".
Impact of disclosures which received helpful responses		
Integrating previously shameful and avoided aspects of self into new narratives	Recognising impact of abuse	*"Once I committed to long-term therapy, I began to see how the process of opening up and feeling the pain and having someone witness it, and the stories connected with that pain, were vital to healing."*
	Improved self-understanding	
	Making connections	*For one survivor, the road to recovery began with overcoming the homophobia he had internalized. I felt dirty. I felt like I was becoming gay because I was sexually abused and that sort of thing. I've come to understand myself better in that respect now.*
	Joining the dots	
	Finding a voice	*I ended up becoming used to, you*

	Telling the story - going public	*know, telling that [disclosure] as part of my narrative, like it was part of my life." Similarly, Daniel explained that disclosing had become easy for him: "I'm used to telling my story so [it's not] hard anymore."*
Narrative and interactional repositioning from "victim" to "survivor" and "thriver"	Positive re-interpretation	*"Seeking help has helped me see myself as courageous rather than a victim."*
	Personal growth	'see things in perspective' and 'recognise the strength that it has taken to survive'.
	Healing through talking	*"I've found for my own self, great healing power in truth. When I'm someplace where I actually tell the truth about what really happened, it transforms, it changes my body chemistry." Shame, he said, "is something that tends to evaporate when you talk about it."*
	Transformative power of disclosure	*All of the thirty-nine men suggested that speaking about experiences of sexual abuse is the hardest but most important step in productive coping. Breaking away from suppression and self-blame was often central to men's advice about how others could cope best with the abuse.*

Impact of disclosures which received unsupportive responses	Shutting down /abandoning help-seeking	*"After seeing the [psychologist] … and having him laugh in my face about the abuse by my female baby-sitter … . I decided that I didn't want to go back and see a counselor' (Male #6).*
	Sense of distrust and betrayal	*"At the time [of disclosure], I felt crazy. The [negative professional] reaction made me feel more crazy …*
	Further destablisation	*"being made to feel like a freak"*
	Feeling re-traumatised	*"[Having abuse denied] creates shame, because I'm not being believed and this is actually my reality . . . it's a really shattering experience . . . the first person I told didn't believe me. That probably led to me going completely insane."*
	Anger, confusion and doubt	*"then you look across and see a look of what you might perceive to be disbelief in somebody's eyes and you're wondering inside yourself, you know about, maybe I am crazy and it didn't really happen or it wasn't like that or, you're supposed to be a man and it wasn't that bad and just shake it off and carry on."*
	Questioning and denying the sexual abuse	*"I thought that the professionals were right—the sexual abuse by my mom and sister couldn't have been that bad. It seemed like more trouble than it was worth trying to deal with it. [The reaction] silenced me … it shut me down"*
		"The message that I got from the psychologist was there's no problem and that I should consider myself lucky that I had sexual contact with a woman at such a young age [6]. [After the appointment] I told myself, just shut up, and don't worry about it. For the following 4 to 5 years, I tried to convince myself that I didn't have a problem."

Impact of non-disclosure		
Remaining stuck and out of touch with true self	Burden of secrecy	*"When you have a secret, like a heavy burden on your shoulders, there is always a kind of wall between you and the rest of the world."***
	Fear of discovery	
	Nondisclosure as isolation and unable to move forward	*"It is probably the time I look the toughest is the time I am the most scared ... I express a lot of my emotions through other things like clothing, you know, stuff like that. I've even had more people come up to me and say that's a mask for me."*
	False /alienated sense of self	''I just saw that my life was, was slipping by me, and I had already alienated myself from my family. There was no family, no friends.''
	Wearing a mask	*''I mean I've been packing this stuff around for a long, long time. And I've been running from it and I've been afraid and I am, you know, running out of time. My life is passing me by.''*
Relationship difficulties	Lack of trust - unable to confide in partner	*'I always felt very bad about this, not being able to reveal what happened… I felt I was lying to her and hiding something and that is not conducive to a relationship'.*
	Problems with intimacy and sexual dysfunction	*"The biggest thing for me growing up in my late twenties was the ability to develop a relationship with the opposite sex. You wanted to get married, but you couldn't say anything."*
Regret over previous non-disclosure	Regret over not doing more to stop the abuse at the time	*"I wish I would have been able to, uh, been open and honest with her [late mother], and, and, I also want, I also wonder why she didn't know or, uh, supposedly didn't know, and didn't do anything about it."*
	Regret over not taking legal action	
	Regret over not being honest with loved ones	*"I blamed myself not having the courage to tell my parents, um, [not having] the courage to tell someone."*

Data-gathering Style in Individuals with Autism Spectrum Conditions: An Examination of Its Relationship with Paranoia Using the Beads Task

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Final Word Count after Amendments: 7224 (excluding abstract, tables and references)

Intended Journal: Journal of Autism and Developmental Disorders

This journal was chosen due to its topic focus and the fact that previous research that guided the rationale for this study has been published there.

Paranoia, defined as the presence of unfounded beliefs that others intend to harm the self, exists on a continuum in clinical and non-clinical populations. Paranoid thoughts are regularly experienced by 10-15% of the general population and range from mild threat beliefs and ideas of reference to persecutory delusions which in their most strongly held, distressing and preoccupying form present symptoms of acute psychosis (Daniel Freeman, 2007).

While few studies to date have investigated paranoia in people with Autism Spectrum Conditions (ASC), a recent systematic review of seven empirical studies (Spain, Sin, & Freeman, 2016) found evidence for higher levels of paranoia in people with ASC than the general population. People with ASC have also been found to have higher levels of social anxiety (Maddox & White, 2015), private self-consciousness (Blackshaw, Kinderman, Hare, & Hatton, 2001), social cynicism (Pinkham et al., 2012) and persecutory delusions (Abell & Hare, 2005). According to the continuum model of psychosis (Van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2009) these characteristics are implicated in a hierarchy of paranoia (D. Freeman et al., 2005), with paranoid delusions building on the more commonly held evaluation concerns and ideas of reference found in people with social anxiety.

Psychological models of paranoia (Bentall, Corcoran, Howard, Blackwood, & Kinderman, 2001; Salvatore et al., 2012) and delusions (P. A. Garety & Freeman, 1999) propose a number of cognitive mechanisms that are thought to contribute to the development and maintenance of persecutory delusions in psychosis and schizophrenia. These include low self-esteem and negative beliefs about the self (Chadwick, Trower, Juusti-Butler, & Maguire, 2005), theory-of-mind (ToM) deficits, i.e. difficulty with inferring others mental states (Frith & Corcoran, 1996), attentional and attributional biases (Bentall & Kaney, 1989; Bentall, Kinderman, & Kaney, 1994; Lyon, Kaney, & Bentall, 1994) and reasoning biases in the form of reduced data-gathering (P. Garety, Hemsley, & Wessely, 1991).

To date, there is insufficient evidence to ascertain whether these cognitive mechanisms also contribute to the development and maintenance of paranoia and persecutory delusions in people with autism, or whether distinct ASC-specific vulnerability factors may result in a qualitatively different cognitive structure of paranoia in autism (Pinkham et al., 2012; Spain et al., 2016). For example, it has been proposed

that in autism, ToM deficits may combine with frequent negative experience of social interactions, rejection, victimisation and bullying, known to be high for children with ASC (Schroeder, Cappadocia, Bebko, Pepler, & Weiss, 2014) to produce persecutory ideation. Lack of belief flexibility (i.e. high conviction) and being overly detail-focused (weak central coherence) may then make it harder to challenge these ideas (Spain et al., 2016). Previous research comparing individuals with ASC, psychosis and non-clinical TD controls has confirmed higher levels of private self-consciousness amongst people with ASC (Blackshaw et al., 2001; Jänsch & Hare, 2014) but has been unable to find evidence for a contribution of attributional biases (Blackshaw et al., 2001; Craig, Hatton, Craig, & Bentall, 2004).

Reduced data-gathering has most commonly been investigated with a probabilistic reasoning task known as the beads task (Phillips & Edwards, 1966). In this experimental task, individuals are shown two jars containing 100 beads each in two colours with reverse proportions. Participants are told that beads will be drawn from just one of the jars at random, shown to them and then returned to the jar. Participants can ask to see as many beads as they like up to a maximum of twenty, before making a decision as to which jar the beads come from. 'Easy' and 'hard' versions of the task employ colour ratios of 85:15 and 60:40 beads, respectively. The task has been used to assess differences in data-gathering style between individuals with and without delusions (Huq, Garety, & Hemsley, 1988). The most commonly measured variable using the beads task paradigm is draws to decision (DtD). This variable has been dichotomised into presence of a 'jumping to conclusions' (JTC) bias for individuals who request less than three beads (P. Garety et al., 1991).

Other researchers have employed logical equivalents of the beads task using alternative materials. Notably, two studies compared the performance of individuals with persecutory delusions, non-deluded psychiatric and non-clinical controls on the beads task and an emotionally salient equivalent using positive and negative personality trait words instead of beads. Both found that all groups made hastier decisions on the emotionally salient version of the task and concluded that reduced data-gathering is amplified by personally meaningful material (REJ Dudley, John, Young, & Over, 1997; Young & Bentall, 1997).

The JTC bias is people with psychosis is now a well-established phenomenon and has been targeted in cognitive-behavioural interventions (Moritz, Vitzthum, Randjbar, Veckenstedt, & Woodward, 2010). Two recent meta-analyses of research based on the beads task have confirmed that strength of delusional ideation, measured as a continuous variable on the Peters Delusions Inventory (PDI) (Peters, Joseph, & Garety, 1999), is negatively associated with data-gathering in healthy controls and clinical populations (Ross, McKay, Coltheart, & Langdon, 2015) but also suggest that the JTC bias is not a trans-diagnostic phenomenon beyond psychosis (So, Siu, Wong, Chan, & Garety, 2016). It seems important to understand whether the JTC bias is involved in the development and maintenance of paranoia in people with ASC to ensure that cognitive-behavioural interventions can target the appropriate mechanisms (Spain, Sin, Chalder, Murphy, & Happe, 2015).

Research on reasoning style and the presence of data-gathering biases in individuals with ASC has been sparse to date (Brosnan, Lewton, & Ashwin, 2016). However, Brosnan, Chapman and Ashwin (2014) used the 60:40 ratio of the beads task with a group of adolescents with ASC and age-matched controls and found evidence of a 'circumspect reasoning' bias, with the ASC group requesting an average of 9.95 beads compared to 6.87 in the control group. They also found a positive correlation between number of beads requested and strength of autism traits in both groups, measured as a five-item systemising factor (Hoekstra et al., 2011). Elsewhere, Brosnan, Lewton and Ashwin (2016) have explained the circumspect reasoning bias shown by individuals with autism in terms of a dominance of deliberative Type 2 reasoning over 'fast and frugal' intuitive Type 1 reasoning: using a self-report questionnaire and a performance measure of deliberation and intuition, they showed that both, people with a diagnosis of autism and those high in autism traits, show a pattern of deliberative over intuitive reasoning, i.e. a data-gathering style in the opposite direction of the JTC bias. Brosnan and colleagues link their findings to Crespi and Badcock's (2008) neuropsychological model of psychosis and autism as diametrical disorders of the social brain.

While Brosnan et al.'s account of circumspect data-gathering style in autism seems persuasive, a second study examining the performance of a clinical group of individuals with ASC on the beads task found conflicting results. Jänsch and Hare (2014) examined links between paranoia, autism and reduced data-gathering and found that

33% of their ASC sample showed a JTC bias on the 60:40 ratio version of the beads task, while no individuals in the non-clinical group showing this bias. The ASC group were found to request a median number of 5 beads (IQR=6) compared to 10 beads (IQR=3) in the control group. Both differences were found to be statistically significant. While Jänsch and Hare also found significantly higher paranoia scores in the ASC group, intriguingly, the negative correlation between paranoia scores and draws to decision did not reach significance when the groups were analysed separately, though correlation coefficients showed a medium effect size ($r>-0.3$) for the relationship between paranoia and draws to decision in each group.

In light of these recent conflicting findings, this study seeks to clarify the direction of a possible data-gathering bias on the beads task in individuals with ASC and to examine its association with paranoia. While Brosnan et al. recruited their sample from a specialist ASD school unit and reported participants to have no known psychiatric co-morbidities, Jänsch and Hare's study recruited a clinical sample of ASC individuals, many of whom had high levels of mental health co-morbidity, including paranoid ideation. If Brosnan et al's (2014) finding that adolescents individuals with ASC show increased rather than reduced data-gathering compared to TD controls is correct and also holds for adults with ASC (i.e. ASC individuals will request more and not less beads before reaching a decision), could the presence of paranoia act as a moderator on this relationship and lead to individuals with ASC and high levels of paranoid ideation reducing their data-gathering in favour of a more hasty decision-making style? One recent study (Larson et al., 2015) reported an empathsising bias (i.e. higher emphasising and lower systemising scores on the AQ-50) for ASC individuals with a diagnosis of psychosis compared to ASC individuals without psychosis. This suggests that presence of psychosis is associated with a more intuitive (Type 2) reasoning style in individuals with ASC. However, if it can be shown that the 'circumspect reasoning bias' proposed by Brosnan et al. persist in the presence of high levels of paranoia, this would provide initial evidence that reduced data-gathering is not a contributory factor for paranoia in ASC in the same way as it has been suggested to contribute to paranoia in TD individuals. This study seeks to measure paranoia, social anxiety and degree of systemising (as a proxy for presence of a more deliberative (Type 1) reasoning style, so that their influence on the relationship between ASC status and data-gathering style can be examined.

Furthermore, the study seeks to establish whether the effect of task design (neutral versus emotionally salient stimuli) on amount of data-gathering that has previously been reported for individuals with psychosis and non-clinical TD controls might extend to individuals with autism. While TD individuals with and without persecutory delusions have been found to make decisions based on less information if the task materials are emotionally salient (REJ Dudley et al., 1997; Young & Bentall, 1997), it may be speculated whether the data-gathering approach of ASC individuals will be informed by the logically equivalent structure of the two tasks rather than any surface differences in design. Arguably, if impairment in intuitive reasoning leads people with ASC to use a deliberative approach to decision-making (Brosnan et al., 2016), the emotionally salient nature of task materials should not affect performance. Conversely, weak central coherence in individuals with ASC may lead to perceptual salience of current over previous information and result in a greater effect of emotionally laden over neutral stimuli on hasty decision-making, as previously reported for TD populations.

The main research hypothesis for this study is thus formulated as follows: Data-gathering style (measured as draws to decision) will differ between people with and without autism and according to task type (neutral vs emotionally salient stimuli), independent of levels of paranoia, social anxiety and systemising.

Methods

Participants

Two groups of participants were recruited for the study:

(1) Adults with an Autism Spectrum Condition (ASC). This was defined to include individuals with a diagnosis of Asperger Syndrome, High Functioning Autism, Autism, Atypical Autism, Pervasive Developmental Disorder (PDD) and PDD not otherwise specified).

(2) Adults without ASC diagnosis, henceforth referred to as the typically developing group (TD).

Exclusion criteria. All participants: (1) under 18 years of age; (2) completion time <5 minutes or > one hour; (3) multiple entries by the same participant.

ASC group participants: no formal diagnosis of autism.

TD group participants: positive autism screen on the AQ10.

Recruitment. Participants for both groups were recruited via adverts on social media, including Twitter, Facebook groups, websites targeted at people with Autism, mailing lists of the National Autism Society and posters with QR codes displayed in public places. (Refer to Appendix 1 for a list of recruitment sites and the study advert).

Analysis Plan. To test the main hypothesis, a Repeated Measures Multiple Analysis of Covariance (MANCOVA) will be conducted, with presence /absence of ASC as the binary factor, paranoia (GPTS score) as the covariate and draws to decision on the Beads Task and the Survey Task as the two paired response variables.

Preliminary analysis will assess the performance of the clinical measures for each group and will check for collinearity between paranoia, social anxiety and systemising scores, to decide whether social anxiety and systemising make a sufficiently independent contribution to reduced data- gathering and therefore should be controlled for as confounders by adding them as additional covariates to the MANCOVA.

Sample size and power. As resources for estimating sample size for MANCOVA could not be identified, a power calculation for a repeated measures MANOVA was conducted using G*Power (Faul, Erdfelder, Lang, & Buchner, 2007), based on the rationale that the addition of covariates reduces degrees of freedom, therefore the sample size to achieve the same level of power for MANCOVA is slightly smaller than that for MANOVA (Dattalo, 2008). For the sample size calculation (included in Appendix B) alpha and beta were set to conventional levels at .05 and 0.8., respectively and a correlation co-efficient of 0.8 was assumed between the two repeated measures. The sample size required to detect a small to medium effect size (F= 0.25) was calculated as 116 participants in total. For a multiple regression of draws to decision with three predictors (paranoia, social anxiety and systemising) a required sample size of 124 participants was calculated to achieve 80% power to detect a small effect size (r=0.10) for a two tailed test.

Questions on Demographic and Diagnostic Information

All participants were asked to provide information on their age, gender, highest educational qualification, past mental health diagnoses, current mental health difficulties and whether they identified as having an ASC. Participants who identified as having an ASC were asked further questions to establish details of when and where they had received their diagnosis (see Appendix 1 for details).

Clinical Measures

All measures used in this study are freely available and have been included in Appendix 1.

Autism-Spectrum Quotient Screening Tool (AQ-10). The AQ10 is a brief ten-item questionnaire which was developed to provide a 'red flag' for autism sufficiently brief to be used in primary care practice (Allison, Auyeung, & Baron-Cohen, 2012). It is currently recommended as a screening tool in the NICE guideline on Diagnosis and Management of Autism Spectrum Disorder in Adults (CG142, 2012). The questionnaire is composed of the top two most discriminatory items from the AQ-50 and as such is not designed to be internally consistent. The AQ-10 has been reported to have a sensitivity of 79.87% [CI 95%: 69.13% to 90.60%] and a specificity of 87.31% [CI 95%: 76.87% to 95.52%]. It has been judged to perform reasonably similar to the full AQ-50 (Booth et al., 2013).

The AQ-10 was included to enable screening out of possible undiagnosed cases of ASC from the control group.

Autism-Spectrum Quotient (AQ50) - Systemising Factor. The five-item numbers/patterns subscale of the AQ50 (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) was used to measure respondents' degree of "systemising". The subscale was explored by Hoekstra and colleagues (2011), with each item rated on a four point response scale ranging from 0 to 3. The numbers/patterns factors has previously been shown to correlate strongly with the Systemising Quotient Questionnaire (SQ, Wakabashi et al., 2006, cited in Brosnan et al., 2014:515) and has been suggested to be linked to dominance of Type 2 reasoning style in individuals with ASC. The AQ-50 systemising factor was included to enable comparison with previous research (Brosnan et al., 2014),

which found a positive correlation between systemising scores and number of draws to decision on the beads task for ASC and TD individuals (Brosnan et al., 2014).

Green et al. Paranoid Thoughts Scale (GPTS). The GPTS is a 32-item self-report measure composed of two subscales containing 16 items each, measuring ideas of social reference and persecution, respectively. It was developed to provide a measure of paranoia as a continuous variable in clinical and non-clinical populations (Green et al., 2008). Respondents are asked to rate each symptom statement on a scale ranging from 1 ("not at all") to 5 ("totally"). Total score ranges from 32 - 160. The GPTS has been shown to have good test-retest-reliability (intraclass correlation coefficient = .87) and excellent internal consistency (Cronbach's α = 0.90 - 0.95) in clinical and non-clinical populations alike (Green et al., 2008). In line with the continuum model of paranoia, there is no suggested clinical cut-off, but mean scores are reported as 48.8 (SD 18.7) for the non-clinical group and as 101.9 (SD 29.8) for the clinical group.

The scale was chosen because it is a widely used assessment of paranoia with strong psychometric properties, and it fits with the continuum model of paranoia (D. Freeman et al., 2005). It is clearly worded and has good convergent validity with two other measures of paranoia and delusions frequently used in association with the beads task paradigm: the Peters et al. Delusions Inventory (Peters et al., 1999) and the Paranoia Scale (PS, Fenigstein and Vanable, 1992). Significant correlations between the GPTS and these scales are reported as Spearman's ρ=0.43 to 0.39 for the PDI and 0.71 to 0.81 for the PS (Green et al., 2008). The GPTS has been used in previous research examining the performance of ASC individuals on the beads task (Jänsch & Hare, 2014).

Social Anxiety Interaction Scale (SIAS). The SIAS (Mattick & Clarke, 1998) is a 20-item self-report measure designed to tap into the construct of fear of social interaction. It asks respondents to rate their thoughts and feelings in social situations on a five-point scale ranging from 0 (not at all characteristic of me) to 4 (extremely characteristic of me) in line with diagnostic criteria for social phobia and social anxiety. It was developed to assess prevalence, severity, and treatment outcomes of social phobia and social anxiety disorders. The total maximum score is 80 and clinical cut-offs have been suggested as =>34 for social phobia and =>43 for generalised social anxiety. The authors report good internal consistency with Cronbach's alphas ranging from 0.88-0.93 and a test-retest reliability of 0.90.

A measure of social anxiety was included in view of the high levels of social anxiety reported for adults with ASC. The SIAS focuses on fears associated with social interaction rather than fear of negative evaluation or ideas of reference and therefore has minimal overlap with the item statements included in the GPTS.

Experimental Tasks

Beads Task.

This study adapted the 60:40 version of the beads task for computerised presentation (see Appendix 1). The point at which participants opted to make a decision was recorded as a continuous variable (draws to decision, DtD). Decisions made after seeing less than three beads/words were classed as 'jumping to conclusions' and recorded as a categorical variable (JTC bias). After participants had chosen a jar, they were asked to rate how confident they felt in their decision by dragging a slider onto a value between 0 and 100. This was recorded as a continuous variable 'confidence'. Completion time for the task and whether participants chose the correct jar was also recorded.

Survey Task. An emotionally salient and logically equivalent computerised version of the beads task was created based on the instructions and materials employed in two previous studies (REJ Dudley et al., 1997; Young & Bentall, 1997). The survey task presents participants with a series of positive and negative personality traits words (e.g. generous, annoying). They are informed that the words are drawn at random from one of two surveys, one survey describing Person A, who is mostly liked and has been described with positive trait words by 60 out of a 100 people who took part in the survey, and Person B, who is mostly disliked and has been described with negative trait words by 60 out of 100 people. Participants were shown a visual representation of the two surveys and the order of positive and negative words was equivalent to the order of different coloured beads. The survey task generated the same variables as the classic beads task to enable within-group comparisons.

In both versions of the task, the beads /words previously taken from the jar/survey were displayed in order at the bottom of the screen to eliminate the need for

participants to remember previous draws. (Full instructions for both tasks, order of beads/words and screen shots are included in Appendix 1.)

Procedure

All materials were presented online using the Qualtrics online platform to ensure consistency of administration. Order of task type (survey/beads) and task version (blue/yellow beads and positive/negative personality traits) was counterbalanced using the inbuilt randomisation function. After completing the final task, participants were invited to rate their enjoyment of each task on a scale from -10 to +10 and provide qualitative feedback on their experience of the tasks. An overview of the procedure and a flowchart of the order of measures, tasks and randomisation points are provided in Appendix 1.

Ethics

Ethical approval for the study was obtained from the University of Bath Ethics Committee (ref 16-298) which applies the ethical code endorsed by the British Psychological Society. Draft versions of the study materials were piloted with three adults, including an individual with ASC, to gauge approximate completion time, ensure intelligibility of materials and adjust the presentation of tasks to the needs of individuals with ASC. Participants were made aware of their right to withdraw from the study at any point and were assured that no personally identifiable would be stored. On completion, participants received debrief information about the rationale behind the experimental tasks and were provided with links to further information and support for mental health difficulties (PIS, consent form and debrief information are provided in Appendix 1).

Results

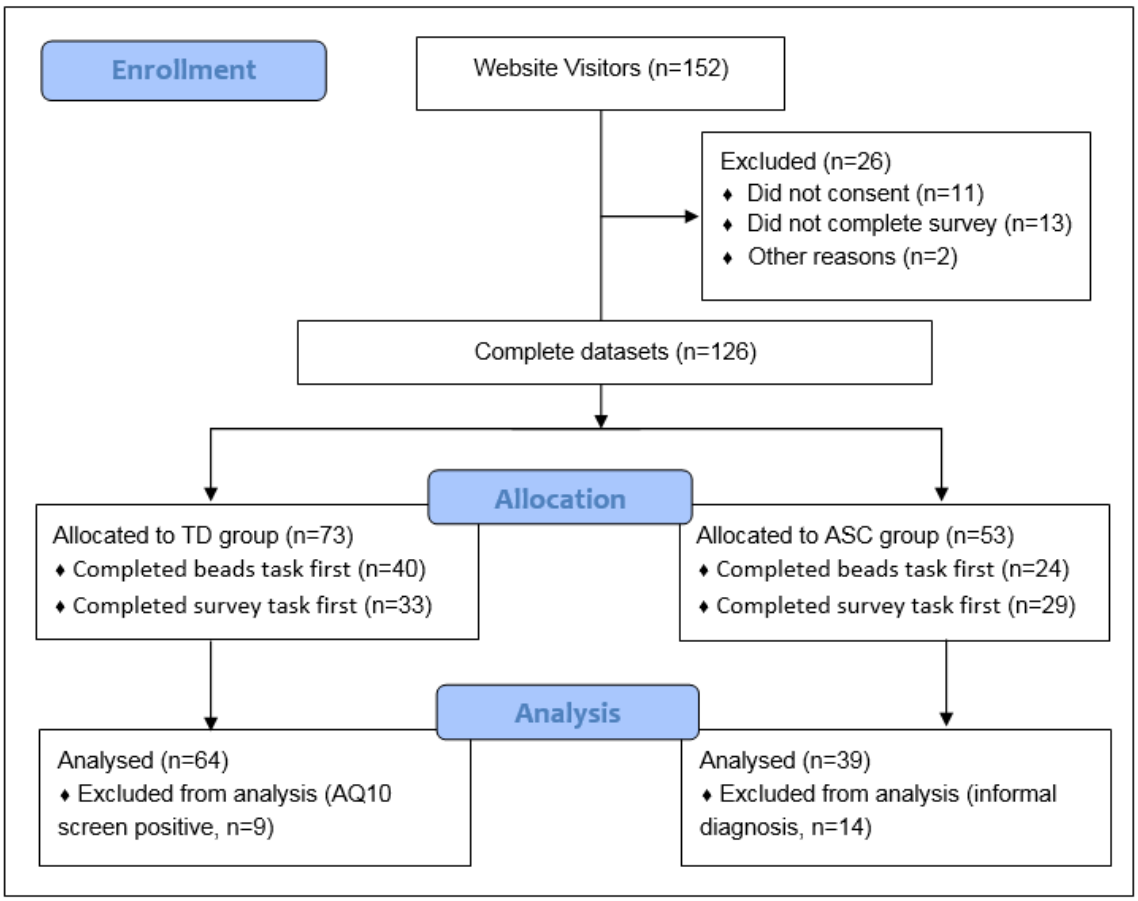

Figure 1: CONSORT Flowchart

Results from 39 participants with an ASC and 64 typically developed controls were included in the analysis. Table 1 shows participant characteristics and differences between groups. The ASC and TD groups differed in age with the TD group being slightly older (TD mean age in years=38.0, sd=11.9; ASC mean age in years 31.9, sd=13.0; t(101)=2.43, p=.019, 95% CI [1.22,10.73]. The odds of having been diagnosed with a mental health problem and for currently experiencing mental health difficulties were 2.4 and 5.6 times higher, respectively, for individuals in the autism group.

Descriptive Data

Figure 1 provides a CONSORT diagram to show flow of participants through the study. Dependent variables comprised scores on clinical measures which were all continuous (GPTS, SIAS, PDI-persecutory ideation item and AQ50-systemising factor) and variables measuring performance on the experimental tasks (DtD, confidence at decision and completion time as continuous variables, and JTC bias and correct jar/survey choice as a categorical variable).

Table 1: Participants' Demographic and Diagnostic Details (N=103)

	TD group (N=64)	ASC group (N=39)	Tests for significance
Gender	male 18 (28%) female 46 (71.9%)	male 17 (43.6%) female 19 (48.7%) other 7.7% (3)	$\chi^2(1)=3.69$, $p>.05$
Highest educational qualification	None 1 (1.6%) GCSE 7 (11.8%) A-Levels 11 (17.7%) 1st degree 20 (32.3%) postgrad degree 22 (35.5%) other 1 (1.6%)	None 1 (2.6%) GCSE 5 (13.2%) A-Levels 16 (42.1%) 1st degree 9 (23.7%) postgrad degree 7 (18.4%) other 0 (0%)	
Ever received a mental health diagnosis	Yes 32 (50%) No 31 (48.4%) Missing 1 (1.6%)	Yes 27 (69.2%) No 11 (28.2%) Missing 1 (2.6%)	$\chi^2(1)=4.01$, $p<.05$*
Currently experiencing mental health difficulties	Yes 13 (20.3%) No 47 (73.4%) Missing 1 (1.6%)	Yes 22 (56.4%) No 14 (35.9%) Missing 3 (7.7%)	$\chi^2(1)=15.11$, $p<.001$***

Reliability of clinical measures was very good for paranoia (GPTS) and social anxiety (SIAS) measures and satisfactory for the systemising factor (AQ50) for each group and for the sample as a whole (see Table 2).

Table 2: Performance of Clinical Measures (Cronbach's alpha)

	TD group (N=64)	ASC group (N=39)	Whole sample (N=103)
AQ50-systemising factor (5 items)	.673	.661	.787
GPTS (32 items)	.972	.966	.970
SIAS (20 items)	.943	.904	.959

Preliminary Data Checks and Revised Analysis Plan

When data were assessed for outliers, normality, linearity and homogeneity of variances through inspection of histograms, boxplots, frequencies and P-P and Q-Q plots, significant skewness and kurtosis were evident in a number of the dependent variables. Non-normality was also confirmed statistically using the K-S test and Levene's test (see Appendix 2).

Review of extreme scores did not suggest obvious reasons for the exclusion or adjustment of these scores, Removal of extreme scores was not feasible as one of the outcomes of interest, the JTC bias, is defined as an extreme score. It was also not possible to transform the data to make it normally distributed The decision was therefore taken to conduct analyses using non-parametric tests (Spearman's rho, Mann-Witney U test, Wilcoxon's Signed Rank Test and Pearson's Chi Square).

The initial research hypothesis was split into five individual hypotheses as specified below to adjust to the constraints placed on analysis arising from the use of non-parametric tests.

1. The ASC group will differ from the TD group in number of draws to decision on both versions of the task.
2. The proportion of individuals showing a JTC bias will differ between the TD and ASC groups.
3. Task design will affect performance for the TD group but not the ASC group, with the TD group predicted to show hastier decision-making (less DtD) on the emotionally salient version of the task (survey task).
4. Paranoia will be negatively associated with draws to decision on the beads task in both groups.
5. Scores on the systemising traits factor (AQ50) will be associated with draws to decisions on the beads task in both groups.

The data met assumptions for non-parametric tests in terms of independent observations. Bootstrapping will be used where possible to increase robustness of tests and take into account the non-nromal distribution of the sample data. Bootstrapped and bias corrected 95% confidence intervals for parameters are reported in square brackets.

Comparison of Clinical Measures between Groups

Bootstrapped t-tests were conducted for normally distributed AQ10 and AQ50 scores and Mann-Witney U tests for GPTS and SIAS scores due to their high levels of skew.

As expected, scores for autism traits (AQ10) and for systemising (AQ50 five-item factor) were higher in the ASC than the TD group, with mean differences in scores of 3.96 points and 5.09 points, respectively. Paranoia and social anxiety were also higher in the ASC group, with median difference in scores of 9 and 31 points, respectively. All between-group differences were highly statistically significant (Table 3).

Paranoia was significantly positively correlated with social anxiety in both groups. For the TD group, Spearman's rho was calculated as: $r_{s.}$=.52, BCa CI [.284,.702]; p<.001 and for the ASC group: $r_{s.}$=.37, BCa CI [.061, .623]; p=.01. GPTS and SIAS scores thus account for 27% of variance in the ranks of scores in the TD group (R^2=0.27) and for 14% of variance for the ASC group.

Table 3: Performance of Clinical Measures

	TD group (N=64)	ASC group (N=39)	Tests for significance
AQ10 score	Mean=3.66 (SD 1.17) Bca CI [3.4, 3.9]	Mean 7.62 (SD 1.42) Bca CI [7.1, 8.1]	t(101)=-15.310, p<.001***
AQ50 systemising factor	Mean=4.76 (SD 3.16) Bca CI [8.9, 10.8]	Mean 9.85 (SD 3.0) CI [4.0, 5.5]	t(101)=-8.076, p<.001***
Paranoia (GPTS)	Mdn=39 (IQR=19.75) Bca CI [36, 44]	Mdn=48 (IQR= 32) Bca CI [42, 58]	U=1,594.50, z=2.36, p=.018**, r=.23
Social Anxiety (SIAS)	Mdn=21 (IQR=21.25) Bca CI [15, 29]	Mdn= 52 (IQR= 21) Bca CI [47, 56]	U=2,231.50, z=6.69, p<.001**, r=.66

Planned Comparisons

Statistical results of between-group comparisons on continuous task performance variables are summarised in Table 4.

Hypothesis 1: The ASC group will differ from the TD group in number of draws to decision on both versions of the task.

The ASC group requested a greater number of beads on both versions of the task, with a median group difference of 1.5 beads for the beads task and 3.5 words for the survey task. Both differences were statistically significant. Beads task: U=1,595.50, z= 2.38, p=.017, r=0.24. Survey task: U=1,659.00, z=2.84, p=.005, r=0.28.

Table 4: Continuous Dependent Variables Derived from Task Performance

	TD group (N=64)	ASC group (N=39)	Tests for significance
Draws to decision beads task	Mean=6.61 (SD= 5.29) Mdn= 7.5 (IQR= 9.0)	Mean= 9.5 (SD= 5.38) Mdn= 9.0 (IQR= 7.0)	U=1,595.50, z=2.39, p= .017**
Draws to decision survey task	Mean 6.17 (SD= 5.38) Mdn 6.0 (IQR= 9.75)	Mean 9.68 (SD= 5.76) Mdn 9.5 (IQR= 8.0)	U=1,659.00, z=2.84, p=.005**
Confidence beads task (0 to 100)	Mean 61.92 (SD= 23.27) Mdn= 70.0 (IQR=29.0)	Mean 61.68 (SD= 17.50) Median 60.5 (IQR= 22.75	U=1,158.00, z=-.613, p=.540
Confidence survey task (0-100)	Mean 66.17 (SD= 21.52) Mdn=69.0 (IQR= 29.00)	Mean 66.29 (SD= 22.47) Mdn=68.0 (IQR= 23.75)	U=1,237.00, z=-.146, p=.989
Completion time beads task (in seconds)	Mean 37.15 (SD= 23.57) Mdn=35.45 (IQR= 31.08)	Mean 47.80 (SD= 40.62) Mdn=45.78 (IQR= 58.87)	U=1,393.00, z=-.986, p=.257
Completion time survey task (in seconds)	Mean 38.0 (SD= 23.63) Mdn=36.45 (IQR=31.08)	Mean 48.72 (SD= 40.88) Mdn=46.62 (IQR= 58.88)	U=1,395.00, z=-.999, p=.252

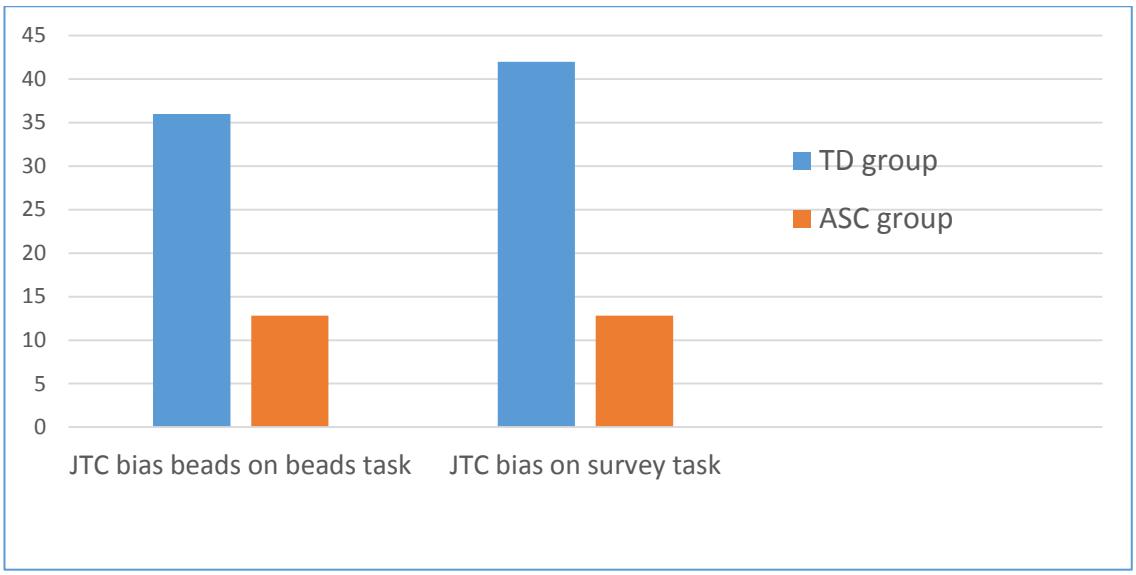

Figure 2: Percentage of individuals jumping to conclusions

Hypothesis 2: The proportion of individuals showing a JTC bias will differ between the TD and ASC groups.

There was a significant negative association between autism and the JTC bias (defined as drawing less than 3 beads) on both versions of the task. Based on the odds ratio, the odds of jumping to conclusions were 4.6 times higher for individuals in the TD group than the ASC group (3.7 times on beads task; 4.9 times on the survey tasks). Results are shown in Figure 2 and Table 5.

Table 5: JTC Bias on Tasks for TD and ASC Groups

	TD group (N=65)	**ASC group (N=39)**	**Tests for significance**
JTC bias beads task	No=41 Yes=23	No=34 Yes=5	$\chi^2(1)=6.54$, p=.011*
JTC bias survey task	No=37 Yes=27	No=34 Yes=5	$\chi^2(1)=9.76$, p=.002**
JTC bias either task	No=35 Yes=29	No=33 Yes=6	$\chi^2(1)=9.67$, p=.002**

Hypothesis 3: Task design will affect performance for the TD group but not the ASC group, with the TD group predicted to show hastier decision-making (less DtD) on the emotionally salient version of the task (survey task).

Wilcoxon's Signed Rank Test was used to compare the groups (ASD and TDC) on the two task versions. Task design was not found to significantly affect performance in either group. TD group: T=220, p=.407, r=-.007; ASC group: T=110, p=.851, r=.006. For the TD group, mean and median of DtD decreased by 0.44 and 1.5 beads, respectively, on the survey task. In the ASC group, mean and median of DtD increased by 0.18 and 0.5 beads, respectively, on the survey task.

Hypothesis 4: Paranoia will be negatively associated with draws to decision on the beads task in both groups.

There was no discernible correlation between paranoia and DtD on the beads task for either group: TD group, r_s=-170 BCa CI [.-387, .080], p=.180; ASC group r_s=-.135 BCa CI [-.444, .208], p=.413.

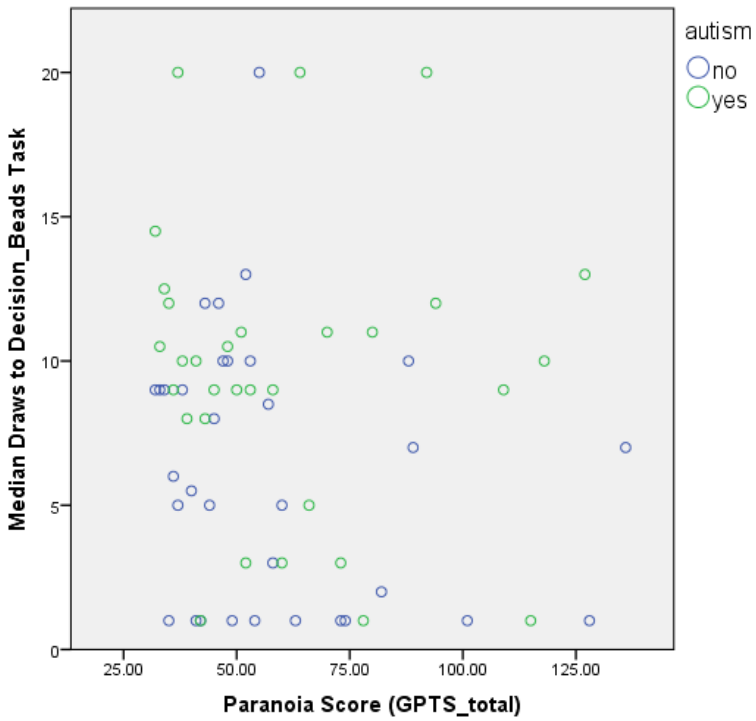

Figure 3: *Scatterplot of Paranoia Scores and Draws to Decision on the Beads Task*

Visual inspection of the scatterplot (Figure 3) for performance on the beads task suggests that individuals who showed a JTC bias did not have higher levels of paranoia than those who did not.

Hypothesis 5: Scores on the systemising traits factor (AQ50) will be associated with draws to decisions on the beads task in both groups.

There was no statistically significant relationship between systemising and DtD on the beads task for either group, (TD group r_s=-.060 BCa CI [.-299, .201], p=.318; ASC group, r_s=-303 BCa CI [-.551, -.015] p=.064.

Exploratory Analysis

Posthoc exploratory analysis found no significant differences in degree of confidence at decision or in completion time between groups (Table 4). There was also no difference in the proportion of individuals who chose the correct jar between the TD and the ASC group, $\chi^2(1)$=.302, p=.741.

Discussion

Summary of Findings

Data-gathering style was investigated in 39 adults with ASC and 64 typically developed controls using two probabilistic reasoning tasks: the beads task and an emotionally salient equivalent. Despite higher levels of paranoia and social anxiety, the ASC group requested more information and were less likely to show a JTC bias than the TD group on both tasks. Results suggest that data-gathering style may not be a contributory factor for paranoia in autism, consistent with the proposal of a differential cognitive structure of paranoia in individuals with ASC.

The nature of task materials (i.e. the neutral beads task versus the emotionally salient survey task) did not seem to affect performance, with no difference between draws to decision between tasks.

Contrary to previous findings (Brosnan et al., 2014), higher scores on the AQ50 systemising factor were not associated with greater number of draws to decision. However, in line with Brosnan et al.'s previous findings, exploratory analysis found no difference in confidence at decision between the two groups. This suggests that individuals with ASC make decisions at similar thresholds of certainty compared to TD individuals, but required a greater amount of information to reach certainty.

Surprisingly, and in contrast to previous findings for TD individuals with persecutory ideation, there was no association between paranoia scores and draws to decision for either of the groups. These findings conflict with Jänsch and Hare's (2014) study, which found that 33% of their ASC sample showed a JTC bias on the 60:40 version of the beads task. Levels of paranoia were slightly higher and more widely distributed in their ASC sample (Mdn=58, IQR=63), however, it seems unlikely that a 10 point difference in GPTS median scores would account for the observed difference in task performance between the two studies.

This study found a comparatively high percentage of individuals (36%) in the TD group demonstrating a JTC bias. Previous research typically reports presence of a JTC bias for between 10-20% of non-clinical controls groups on the 60:40 version of the beads task (Fine et al, 2007). While high levels of mental health comorbidities in the TD group (50% had received at least one previous mental health diagnosis) may have contributed to a greater proportion of the group jumped to conclusions on either version of the task, it should also be considered whether the medium of task administration, i.e. anonymous online completion, may have impacted on participants' level of engagement with the tasks. In other words, did fewer individuals commit to responding to task instructions and the decision-making tasks with due levels of diligence, or did the absence of a co-present investigator being present lead people to terminate the tasks prematurely? The high internal consistency achieved for the social anxiety measure (SIAS) in both groups, which included a number of reverse scored items and which participants were asked to complete between the two tasks, suggests that participants made considered choices on questionnaire items. High degrees of correlation between amounts of information requested and confidence ratings at point of decision-making for the two tasks further suggest that participants were adequately engaged with the tasks themselves. Arguably, absence of a co-present researcher removes the risk of participants feeling pressurised to

reach a decision quickly due to demand characteristics. It is therefore unlikely that the high proportion of TD individuals found to show a JTC bias in this study is attributable to the tasks being administered online.

There was a statistically significant difference in age between the two groups, with individuals in the TD group being on average 6.1 years older than those in the ASC group. Some scholars (Lunt et al., 2012) have suggested that jumping to conclusion may represent a cognitive deficit rather than a bias and may be associated with impairments in temporal sequencing or working memory (Robert Dudley, Cavanagh, Daley, & Smith, 2015). As working memory reduces with age, age should be considered as a potential confounding factor for task performance. However, meta-analysis of by Ross et al. (2013) of 38 clinical and non-clinical samples did not identify age as a sample-level moderator to be a statistically significant predictor of effect size. In the present study, age did not show a significant correlation with draws to decision on task performance in either group (TD group, r_s=.073, BCa 95% CI [.-177, .310], p=.565. and ASC group, r_s=-.024, BCa 95% CI [.-534, .063], p=.851) and therefore is unlikely to have confounded between-group differences in task performance.

The here presented findings conflict with a host of previous research which has found a dose-response relationship of paranoia and delusions with reduced-data-gathering and presence of a JTC bias (Ross et al., 2015; So et al., 2016). These findings are difficult to explain and warrant further investigation. Individuals with ASC do not present a homogenous group and future studies may want to differentiate between different autism profiles, in particular with regard to the presence of alexithymia. If circumspect reasoning style and a logical approach to decision-making result from impairments in intuitive Type 1 reasoning, as proposed by Brosnan et al. (2016), it is possible that individuals with ASC but intact interoceptive abilities may make hastier decisions on the tasks than their alexithymic counterparts (Shah, Catmur, & Bird, 2016).

However, the here presented findings, and in particular, the null findings, should be treated with caution due to issues of statistical power and multiple comparisons, which may have increased risks of Type 2 and Type 1 errors, respectively. The analysis only had 69% power to detect a statistically significant small to medium effect size (>0.3) of an association between paranoia and draws to decision in the TD group for a two-tailed hypothesis. For the ASC group, the power to find a statistically significant small effect size

was 48%. Revisions to the original analysis plan that were required in view of the non-linear and non-normal distribution of the data meant that several non-parametric tests had to be employed to examine aspects of the original research hypothesis separately instead of being able to employ a single test (MANCOVA). This resulted in multiple comparisons being made and therefore inflated the likelihood of a Type 1 error. Five planned comparisons (3 x Chi square and 2 x Mann-Whitney U) were required to test for between-group differences in data-gathering on the two tasks between ASC and TD individuals. Four planned comparisons tested for correlations between clinical measures (paranoia and systemising) and draws to decision on either task. A further four posthoc tests were carried out to compare task performance between groups with regard degree of confidence at decision-making and completion time.

Methods to keep the likelihood of Type 1 error at an acceptable level despite multiple tests being carried out on the same data include selection of boot-strapping when carrying out statistical tests in SPSS and the Bonferroni correction (Field, 2013). The Bonferroni correction is applied by dividing the customary alpha level of .05 by the number of comparisons carried out on the same data.

If a Bonferroni correction was applied to the tests carried out in this study, only alpha level of >.01 should be considered statistically significant, thereby keeping the likelihood of a Type 1 error at the conventional level of 1 in 20. Such a correction would have resulted in rendering the difference between the ASC and TD groups for draws to decision and presence of JTC bias on the beads task statistically nonsignificant, whereas statistically significant differences on the survey task would have been upheld.

The null findings with regard to an association between paranoia or systemising and draws to decision on either version of the task should be interpreted carefully in view of the reduced power of non-parametric compared to parametric tests and the fact that the actual sample size only provided 50% and 70% power for the ASC and TD groups, respectively, to detect a small to medium effect size of 0.3. Nevertheless, visual inspection of scatterplots mapping paranoia and systemising scores against draws to decision confirm the absence of even a non-significant trend for both groups with regard to systemising and in the ASC group with regard to paranoia.

Limitations of this Study

This study was designed as an anonymous online survey to maximise recruitment of community samples of people with ASC and typically developed controls within a short time-frame. Self-selection of participants resulted in unequal groups with regard to sample size, age and gender. While the online format ensured consistency in the administration of the experimental tasks, removed demand characteristics with regard to draws to decision and reduced missing data, it meant that participants' understanding of instructions and engagement with the tasks could not be observed or corrected. Materials were piloted with an ASC participant and revised to improve readability, but qualitative feedback given at the end of the survey (Appendix 1) suggests that a couple of participants may nevertheless have struggled with comprehending the task instructions. Miscomprehension has been highlighted as a potential confounder for the beads task (Balzan, Delfabbro, & Galletly, 2012) and while other participants' responses suggested that they had understood the instructions, assessment of comprehension may be desirable to include in future research using this paradigm.

Autism Spectrum Disorder as a diagnostic category is characterised by substantial heterogeneity, with recent changes in DSM-5 codes and criteria reflecting diversity in the possible combination of impairments in the areas of communication, social interaction and social imagination and thought flexibility Researchers are now starting to pay closer attention to how severity of specific impairments in relation to each other may influence individual performance on social and non-social tasks. In this study, participants who identified as having an ASC were not differentiated further into subtypes of Autism Spectrum Disorder. Reliance on online recruitment methods also meant that accuracy of autism diagnosis could not be independently verified. Instead, validity of self-reported ASC status was assessed using a series of carefully designed questions and a short autism screening instrument: those without formal ASC diagnosis and those scoring positive on the screen were excluded from the ASC group and TD group, respectively. It is therefore not possible to assess to what extent the findings of this study are representative of individuals with different subtypes of autism.

There was gender imbalance between groups, with the TD group having a higher proportion of female participants than the ASC group. While this difference did not reach statistical significance, the proportion of females in the ASC group was also high (49%) and not representative of the 4:1 ratio of males to females currently diagnosed with autism in the general population. However, with regard to reasoning style, Brosnan et al. (2016) suggest that autism traits are distributed similarly for males and females with an autism diagnosis. Similarly, gender has not been identified as a relevant variable for performance on the beads task in previous research.

The study relied on self-report measures of social anxiety, paranoia and presence of persecutory delusions that while also employed in other studies with ASC participants have not been validated in this population. However, reliability data on the performance of these measures within the two groups and the entire sample were shown to have good internal consistency.

There is currently no appropriately validated instrument for measuring levels of paranoia in autism. While previous studies using instruments such as the PS, PDI and GPTS have consistently report higher levels of paranoia for individuals with ASC, it might be argued that higher scores on these measures simply reflect that individuals with ASC are more likely to struggle with inferring other people's social intentions due to impairments in Theory of Mind skills and are more likely to have experienced negative social interactions, bullying and marginalisation from peer groups (Maddox & White, 2015; Schroeder et al., 2014). Affirmative responses to questionnaire items that ask about experiences of being judged, being laughed at, and of others dropping hints, being hostile or trying to annoy the person (GPTS items A3, A4, A6, B5, B15) thus may represent accurate descriptions of the social experiences of individuals with ASC instead of indicating presence of ideas of reference and persecutory ideation. Furthermore, the fact that ASC is characterised by greater cognitive rigidity and fixity of beliefs means that questionnaire items that ask about level of conviction are likely to elicit maximum scores from individuals with ASC. When piloting the study materials, a participant with ASC identified a problem with the question 'how true do you think this belief is?" as the idea of holding a belief without also believing that it was true appeared nonsensical to this individual. Therefore, there is a possibility that the higher levels of paranoia observed for individuals with ASC are an artefact arising from criterion contamination. Future research

should employ observational measures of paranoia (Daniel Freeman et al., 2008) in addition to standardised measures when examining paranoia in individuals with ASC.

The study did not include a measure of IQ. Previous research in the context of first episode psychosis has suggested that neurocognitive functioning, and specifically working memory deficits, may affect task performance (Falcone et al., 2014), while meta-analysis of 38 studies (Ross et al., 2015) examining the relationship between the JTC bias and delusions did not find evidence for an indepdent effect of IQ itself. This study included a visual aid memoir of previously drawn beads and words to minimise demands on working memory. Nevertheless, future research should investigate the possible impact of working memory deficits on the JTC bias.

Directions for Future Research

This study presents some preliminary evidence that CBT interventions targeting reasoning style as a contributory factor in paranoia may need to be adapted for individuals with ASC, as reduced data-gathering does not seem to be an issue for this group. Regarding an alternative conceptualisation of paranoia in autism, it may be speculated on the basis of clinical presentations whether paranoia in ASC has more of a 'social anxiety feel' to it, i.e. a general sense of threat from others rather than well-developed ideas about conspiracy theories or specific harmful people, plots and consequences (Stopa, Denton, Wingfield, & Taylor, 2013). Large longitudinal studies as well as qualitative research methods may be helpful in exploring the aetiology of paranoia in autism, e.g. tracing the influence of adverse life experiences such as e.g. bullying, social interaction difficulties and isolation.

Regarding the finding of higher than average levels of paranoia in individuals with ASC, for which this study has provided further evidence, Freeman et al. (2008) have identified anomalous experiences, and in particular, chemo-sensation, as a possible predictor for the development of paranoia beyond social anxiety in some individuals (D Freeman et al., 2008). This is an interesting consideration in the context of autism, as many individuals with ASC report sensory sensitivities, and warrants further investigation as a vulnerability factor for the development of paranoia.

References

Abell, F., & Hare, D. J. (2005). An experimental investigation of the phenomenology of delusional beliefs in people with Asperger syndrome. *Autism*, 9(5), 515-531.

Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward brief "red flags" for autism screening: the short autism spectrum quotient and the short quantitative checklist in 1,000 cases and 3,000 controls. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(2), 202-212. e207.

Balzan, R., Delfabbro, P., & Galletly, C. (2012). Delusion-proneness or miscomprehension? A re-examination of the jumping-to-conclusions bias. *Australian Journal of Psychology*, 64(2), 100-107.

Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The autism-spectrum quotient (AQ): evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, 31(1), 5-17.

Bentall, R. P., Corcoran, R., Howard, R., Blackwood, N., & Kinderman, P. (2001). Persecutory delusions: a review and theoretical integration. *Clinical Psychology Review*, 21(8), 1143-1192.

Bentall, R. P., & Kaney, S. (1989). Content specific information processing and persecutory delusions: an investigation using the emotional Stroop test. *British Journal of Medical Psychology*, 62(4), 355-364.

Bentall, R. P., Kinderman, P., & Kaney, S. (1994). The self, attributional processes and abnormal beliefs: towards a model of persecutory delusions. *Behaviour Research and Therapy*, 32(3), 331-341.

Blackshaw, A. J., Kinderman, P., Hare, D. J., & Hatton, C. (2001). Theory of mind, causal attribution and paranoia in Asperger syndrome. *Autism*, 5(2), 147-163.

Booth, T., Murray, A. L., McKenzie, K., Kuenssberg, R., O'donnell, M., & Burnett, H. (2013). Brief report: An evaluation of the AQ-10 as a brief screening instrument for ASD in adults. *Journal of Autism and Developmental Disorders*, 43(12), 2997.

Brosnan, M., Chapman, E., & Ashwin, C. (2014). Adolescents with autism spectrum disorder show a circumspect reasoning bias rather than 'jumping-to-conclusions'. *Journal of Autism and Developmental Disorders*, 44(3), 513-520.

Brosnan, M., Lewton, M., & Ashwin, C. (2016). Reasoning on the autism spectrum: A dual process theory account. *Journal of Autism and Developmental Disorders*, 46, 2115.

Chadwick, P., Trower, P., Juusti-Butler, T.-M., & Maguire, N. (2005). Phenomenological evidence for two types of paranoia. *Psychopathology*, 38(6), 327-333.

Craig, J. S., Hatton, C., Craig, F. B., & Bentall, R. P. (2004). Persecutory beliefs, attributions and theory of mind: comparison of patients with paranoid delusions, Asperger's syndrome and healthy controls. *Schizophrenia Research*, 69(1), 29-33.

Crespi, B., & Badcock, C. (2008). Psychosis and autism as diametrical disorders of the social brain. *Behavioral and Brain Sciences*, 31(3), 241-261.

Dattalo, P. (2008). Determining sample size: Balancing power, precision, and practicality: Oxford University Press.

Dudley, R., Cavanagh, K., Daley, K., & Smith, S. (2015). Reasoning and Delusions. In N. Galbraith (Ed.), *Aberrant Beliefs and Reasoning* (pp. 55-69). London: Taylor and Francis.

Dudley, R., John, C. H., Young, A., & Over, D. (1997). The effect of self-referent material on the reasoning of people with delusions. *British Journal of Clinical Psychology*, 36(4), 575-584.

Falcone, M. A., Murray, R. M., Wiffen, B. D., O'Connor, J. A., Russo, M., Kolliakou, A., . . . Paparelli, A. (2014). Jumping to conclusions, neuropsychological functioning, and delusional beliefs in first episode psychosis. *Schizophrenia Bulletin*, 41(2), 411-418.

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39, 175-191.

Fenigstein, A., & Vanable, P. A. (1992). Paranoia and self-consciousness. *Journal of Personality and Social Psychology*, 62(1), 129.

Field, A. (2013). Discovering Statistics using IBM SPSS Statistics: Sage.

Freeman, D. (2007). Suspicious minds: the psychology of persecutory delusions. Clinical Psychology Review, 27(4), 425-457.

Freeman, D., Garety, P. A., Bebbington, P. E., Smith, B., Rollinson, R., Fowler, D., . . . Dunn, G. (2005). Psychological investigation of the structure of paranoia in a non-clinical population. *The British Journal of Psychiatry*, 186(5), 427-435.

Freeman, D., Pugh, K., Antley, A., Slater, M., Bebbington, P., Gittins, M., . . . Garety, P. (2008). Virtual reality study of paranoid thinking in the general population. *The British Journal of Psychiatry, 192*(4), 258-263.

Frith, C. D., & Corcoran, R. (1996). Exploring 'theory of mind'in people with schizophrenia. *Psychological Medicine*, 26(3), 521-530.

Garety, P., Hemsley, D., & Wessely, S. (1991). Reasoning in deluded schizophrenic and paranoid patients: biases in performance on a probabilistic inference task. *The Journal of Nervous and Mental Disease*, 179(4), 194-201.

Garety, P. A., & Freeman, D. (1999). Cognitive approaches to delusions: a critical review of theories and evidence. *British Journal of Clinical Psychology*, 38(2), 113-154.

Green, C., Freeman, D., Kuipers, E., Bebbington, P., Fowler, D., Dunn, G., & Garety, P. (2008). Measuring ideas of persecution and social reference: the Green et al. Paranoid Thought Scales (GPTS). *Psychological Medicine*, 38(01), 101-111.

Hoekstra, R. A., Vinkhuyzen, A. A., Wheelwright, S., Bartels, M., Boomsma, D. I., Baron-Cohen, S., . . . van der Sluis, S. (2011). The construction and validation of an abridged version of the autism-spectrum quotient (AQ-Short). *Journal of Autism and Developmental Disorders*, 41(5), 589-596.

Huq, S., Garety, P., & Hemsley, D. (1988). Probabilistic judgements in deluded and non-deluded subjects. *The Quarterly Journal of Experimental Psychology*, 40(4), 801-812.

Jänsch, C., & Hare, D. J. (2014). An Investigation of the "Jumping to Conclusions" Data-Gathering Bias and Paranoid Thoughts in Asperger Syndrome. *Journal of Autism and Developmental Disorders*, 44(1), 111-119.

Larson, F. V., Lai, M.-C., Wagner, A. P., Baron-Cohen, S., Holland, A. J., & Consortium, M. A. (2015). Testing the 'Extreme Female Brain'theory of psychosis in adults with autism spectrum disorder with or without co-morbid psychosis. *PLoS One, 10*(6), e0128102.

Lunt, L., Bramham, J., Morris, R. G., Bullock, P. R., Selway, R. P., Xenitidis, K., & David, A. S. (2012). Prefrontal cortex dysfunction and 'jumping to conclusions': bias or deficit? *Journal of Neuropsychology, 6*(1), 65-78.

Lyon, H. M., Kaney, S., & Bentall, R. P. (1994). The defensive function of persecutory delusions. Evidence from attribution tasks. *The British Journal of Psychiatry*, 164(5), 637-646.

Maddox, B. B., & White, S. W. (2015). Comorbid social anxiety disorder in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(12), 3949-3960.

Mattick, R. P., & Clarke, J. C. (1998). Development and validation of measures of social phobia scrutiny fear and social interaction anxiety. *Behaviour Research and Therapy*, 36(4), 455-470.

Moritz, S., Vitzthum, F., Randjbar, S., Veckenstedt, R., & Woodward, T. S. (2010). Detecting and defusing cognitive traps: metacognitive intervention in schizophrenia. *Current Opinion in Psychiatry*, 23(6), 561-569.

National Institute for Health and Care Excellence (NICE). (2012). Autism spectrum disorder in adults: diagnosis and management (CG142). Retrieved from doi:https://www.nice.org.uk/guidance/cg142

Peters, E. R., Joseph, S. A., & Garety, P. A. (1999). Measurement of delusional ideation in the normal population: introducing the PDI (Peters et al. Delusions Inventory). *Schizophrenia Bulletin*, 25(3), 553-576.

Phillips, L. D., & Edwards, W. (1966). Conservatism in a simple probability inference task. *Journal of Experimental Psychology*, 72(3), 346.

Pinkham, A. E., Sasson, N. J., Beaton, D., Abdi, H., Kohler, C. G., & Penn, D. L. (2012). Qualitatively distinct factors contribute to elevated rates of paranoia in autism and schizophrenia. *Journal of Abnormal Psychology*, 121(3), 767.

Ross, R. M., McKay, R., Coltheart, M., & Langdon, R. (2015). Jumping to conclusions about the beads task? A meta-analysis of delusional ideation and data-gathering. *Schizophrenia Bulletin*, sbu187.

Salvatore, G., Lysaker, P. H., Popolo, R., Procacci, M., Carcione, A., & Dimaggio, G. (2012). Vulnerable self, poor understanding of others' minds, threat anticipation and cognitive biases as triggers for delusional experience in schizophrenia: a theoretical model. *Clinical Psychology & Psychotherapy*, 19(3), 247-259.

Schroeder, J. H., Cappadocia, M. C., Bebko, J. M., Pepler, D. J., & Weiss, J. A. (2014). Shedding light on a pervasive problem: A review of research on bullying experiences among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(7), 1520-1534.

Shah, P., Catmur, C., & Bird, G. (2016). Emotional decision-making in autism spectrum disorder: the roles of interoception and alexithymia. *Molecular Autism*, 7(1), 43.

So, S. H.-w., Siu, N. Y.-f., Wong, H.-l., Chan, W., & Garety, P. A. (2016). 'Jumping to conclusions' data-gathering bias in psychosis and other psychiatric disorders—Two meta-analyses of comparisons between patients and healthy individuals. *Clinical Psychology Review*, 46, 151-167.

Spain, D., Sin, J., Chalder, T., Murphy, D., & Happe, F. (2015). Cognitive behaviour therapy for adults with autism spectrum disorders and psychiatric co-morbidity: A review. *Research in Autism Spectrum Disorders*, 9, 151-162.

Spain, D., Sin, J., & Freeman, D. (2016). Conceptualising paranoia in ASD: A systematic review and development of a theoretical framework. *Research in Autism Spectrum Disorders*, 25, 97-111.

Stopa, L., Denton, R., Wingfield, M., & Taylor, K. N. (2013). The fear of others: a qualitative analysis of interpersonal threat in social phobia and paranoia. *Behavioural and Cognitive Psychotherapy*, 41(02), 188-209.

Van Os, J., Linscott, R. J., Myin-Germeys, I., Delespaul, P., & Krabbendam, L. (2009). A systematic review and meta-analysis of the psychosis continuum: evidence for a psychosis proneness–persistence–impairment model of psychotic disorder. *Psychological Medicine*, 39(2), 179-195.

Young, H. F., & Bentall, R. P. (1997). Probabilistic reasoning in deluded, depressed and normal subjects: Effects of task difficulty and meaningful versus non-meaningful material. *Psychological Medicine*, 27(02), 455-465.

Appendix 1: Supplementary Study Materials

Target Journal Information

Letter of Approval from University of Bath Ethics Committee

Study Documents

- Study Advert
- List of Recruitment Sites and Channels
- Participant Information Sheet
- Consent Form
- Debrief Information Sheet

Demographic and Diagnostic Questions

Clinical Outcome Measures

- Autism Quotient Screening Instrument (AQ10) and AQ50 Systemising Factor
- Green Paranoid Thoughts Scale (GPTS)
- Social Interaction Anxiety Scale (SIAS)
- Peters Delusions Inventory (PDI) - Item for Persecutory Ideation

Research Procedure Overview

Task Design

- Beads Task Instructions
- Order of Beads (based on Dudley et al. 1997, 60:40 ratio version)
- Survey Task Instructions
- Order of Words for Survey Task (based on Dudley et al. 1997)
- Screenshot: Decide or Continue – Beads Task
- Screenshot: Decide and Rate Confidence –Beads Task
- Screenshot: Decide and Rate Confidence –Survey Task
- Screenshot: Halfway Message
- Screenshot: Rating of Task Enjoyment and Feedback Invitation

Survey Flow

Participant Feedback on Taking Part

TD Group Comments

ASC Group Comments

Target Journal Information

Journal of Autism and Developmental Disorders

Editor-in-Chief: Fred R. Volkmar

ISSN: 0162-3257 (print version)
ISSN: 1573-3432 (electronic version)

Journal no. 10803

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APA Style

Text must be double-spaced; APA Publication Manual standards must be followed.

As of January 20, 2011, the Journal has moved to a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
The blinded manuscript containing no author information (no name, no affiliation, and so forth).
The Author Note

Articles, Commentaries Brief Reports, Letters to the Editor

- The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.
- Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.
- Commentary: Approximately 20-25 double-spaced pages maximum, with fewer references and tables/figures than a full-length article.
- A Brief Report: About 8 double-spaced pages with shorter references and fewer tables/figures. May not meet the demands of scientific rigor required of a JADD article – can be preliminary findings.
- A Letter to the Editor is 6 or less double spaced pages with shorter references, tables and figures.

Style sheet for Letter to the Editor:

- A title page with the running head, manuscript title, and complete author information including corresponding author e-mail information
- The blinded manuscript containing no author information (no name, no affiliation, and so forth):-

  - 6 or less double spaced pages with shorter references, tables and figures

  - Line 1: "Letter to the Editor"

  - Line 3: begin title (note: for "Case Reports start with "Case Report: Title")

  - Line 6: Text begins; references and tables, figure caption sheet, and figures may follow (page break between each and see format rules)

REVIEW YOUR MANUSCRIPT FOR THESE ELEMENTS

1. Order of manuscript pages

Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.

Blinded Manuscript without contact information and blinded Abstract, and References

Appendix

Figure Caption Sheet

Figures

Tables

Author Note

Letter of Approval from University of Bath Ethics Committee

Dr Nathalia Gjersoe Chair, Psychology Ethics Committee E-mail: psychology-ethics@bath.ac.uk	UNIVERSITY OF BATH **Department of Psychology** Bath BA2 7AY · United Kingdom

31st January 2016

Dear Kristina,

Reference number 16-298: Social confidence and decision-making in autism

I am writing to confirm that the Psychology Ethics Committee has provided full ethical approval for the above project.

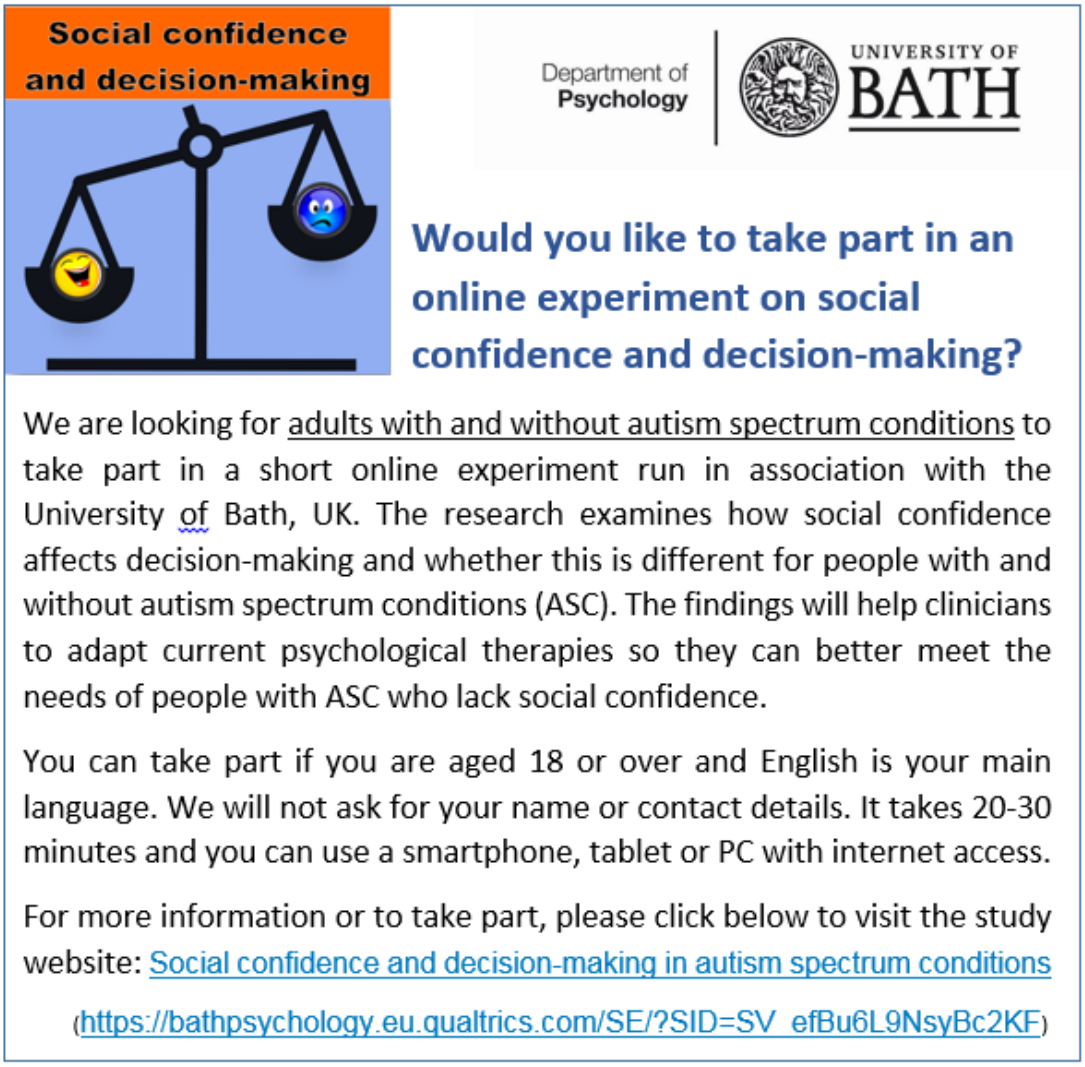
Best wishes with your research.

Dr Nathalia Gjersoe

Chair, Psychology Research Ethics Committee

Study Documents

Study Advert



List of Recruitment Sites and Channels

Participants will be recruited via email lists, autism-specific websites and social media (Facebook). Participants with autistic spectrum conditions will be targeted via the following autism specific mailing lists and websites:

- National Autistic Society (NAS), South Wiltshire Branch Facebook group)
- NAS Avon and Bristol Branch mailing lists
- NAS Bristol Branch mailing list
- AspiesCentral.com
- Reddit.com – Autism subreddit
- Asperger and ASD UK Online Forum
- Ambitiousaboutautism
- Autism UK Forum
- WrongPlanet

Participants without autistic spectrum conditions will be recruited in the same manner as the autism group and also as a convenience sample via social media (Facebook and

Twitter) and may be targeted more selectively to ensure that they are matched as closely as possible to the autism group with regard to age and gender (i.e. the study advert will be modified to specify a more narrow age range or gender, if required).
The outlined approach involving the listed websites and mailing lists has worked well for previous clinical psychology projects conducted at Bath University seeking to recruit these groups online.

Participant Information Sheet

Department of Psychology | UNIVERSITY OF BATH

Research Invitation

Welcome

We are inviting adults **with and without** autism spectrum conditions[1] to take part in a short online experiment run in association with the University of Bath, UK. The research examines how social confidence affects decision-making. We hope that the findings from this research will help clinicians to adapt current psychological therapies so they can better meet the needs of people with autism spectrum conditions who lack social confidence.

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[1] Sometimes this is called "Asperger syndrome", "autism", "atypical autism", "autism spectrum disorder" or "high-functioning autism".

Please read the information below to decide if you would like to take part. Click 'next' at the bottom of the page to advance to the next page.

Why is this study being done?

Research shows that how people make choices in uncertain situations is influenced by how socially confident they feel. People with autism spectrum conditions (ASC) might use different types of information and different reasoning styles to reach decisions than people without ASC.
Lack of social confidence might affect people with ASC in different ways to people without ASC. Ways to help those who struggle with social distrust and anxiety may need to be adapted for people with ASC. We don't currently know how social confidence is linked to reasoning style in people with ASC.
This research examines the relationship between ASC, social confidence and decision-making style.

Who can take part in this study?
We are inviting adults (aged 18 or over) with or without autism spectrum conditions to take part in this study. You need to speak English as a main language.

What will taking part in the study involve?
If you decide to take part in this study, you will be asked to complete three questionnaires and two short decision-making tasks. You will be asked to provide some details about yourself, such as your age, so that we can take these factors into account when analysing the data. **You will not have to give your name or any other identifying information.** You will also have the option not to answer some of the questions if you prefer not to.

All questions and the two tasks can be completed online and will take a total of 20-30 minutes to complete.You can pause at any point and return to where you left off at a later time.

Are there any benefits if I take part?
There are no benefits to you directly from taking part in this study, although we hope that you might find the experience interesting. You will be given further information about the study tasks after you have completed all questions. You will also have the option to provide feedback about your experience of the tasks if you want to.
We hope that the findings from this study will help clinicians to adapt current psychological therapies so they can better meet the needs of people with autism who lack social confidence.

Are there any drawbacks or risks if I take part?
The main drawback of taking part is that you will need to give 20-30 minutes of your time to complete the study. We don't think that there are any risks in taking part, though there is a chance that answering questions about how socially confident you feel and how much you feel you can trust others may make some people feel uncomfortable. After you have completed the tasks and questions, you will be provided with information about helpful websites and support agencies for anyone who experiences difficult thoughts or feelings in the course of taking part in this study.

Who has organised, reviewed and funded this research study? This research is being run by Dr Kristina Bennert and Dr Ailsa Russell in association with the University of Bath. It is part of the doctoral training programme for clinical psychology. The study has been reviewed by the University of Bath Psychology Department Ethics Committee and received a favourable opinion. If you would like to contact Kristina Bennert directly to ask further questions, please email her at k.bennert@bath.ac.uk.

What will happen with the findings from this study?

After the study has been completed the findings will be written up for publication in a scientific journal. Findings may also be presented at meetings and conferences. If you would like to be notified if the study is published or receive a short summary of the findings, please send an email request to Kristina Bennert.

Do I have to take part?

No. It is entirely your choice whether you take part. If you decide to take part and then change your mind that is fine. You can stop completing the tasks and questions at any time. Your data set will not be saved until you have clicked the 'finish' button on the final page. If you have further questions before making a decision about taking part, please contact Kristina Bennert at k.bennert@bath.ac.uk.

What should I do if I want to take part?

If you would like to take part in the study, please click the 'next' button below to be taken to the consent page.

<< Next

Consent Form

Please confirm below whether you have understood the study information given on the previous page. You can go back to the previous page if you need to. If you have any questions please email k.bennert@bath.ac.uk.

I understand the following:

	Yes	No
1. Why the study is being done and why you have been asked to take part	○	○
2. What taking part involves	○	○
3. The possible benefits, drawbacks and risks of taking part	○	○
4. That you have the right to skip questions about yourself or stop completing the tasks at any point and that your data will not be saved until you click the 'finish' button at the end	○	○
5. That findings from this study may be published in a scientific journal and presented at meetings or conferences	○	○
6. That you can email the researcher to request a summary of study findings or with any questions you might have about taking part	○	○

I have answered 'yes' to the above 6 points and agree to participate in the research.

Yes | No

<< Next

Debrief Information Sheet

Many thanks for taking part in this study! Your response has been recorded.

Your participation will contribute to our understanding of the links between social confidence and decision-making, and how this may be different for people with and without autism spectrum conditions (ASC).

Which jar did the beads come from?

We hope you have enjoyed completing the beads task and the person survey task. There is no right or wrong answers to these tasks.

Statistically speaking, there is a greater likelihood of the beads or words coming from one of the jars or one of the person surveys and this likelihood changes during the process of drawing more beads or words. What we were interested in in this study is how many beads or words people ask to see before they feel sufficiently confident to make a decision or 'best guess' in the two different tasks. We also want to know whether the type of task itself makes a difference to how people approach the decision.

People use different data-gathering strategies

Previous studies using these tasks have found that people with ASC want to see more beads - that is, gather more information - before making up their mind than people without ASC.

Previous research has also shown that people who feel anxious about social situations and worry that others might think or talk badly about them, or even try to harm them, tend to want to see only very few beads or words before making up their minds.

Only one study so far has looked at how people with ASC who are socially anxious or worry that others might try to harm them make decisions on the beads task. There have not been any studies which have looked at how the nature of the task itself –beads or personality traits - may affect people's decision-making strategies.

Psychological therapies can help balance unhelpful strategies

Psychological therapies can help people who lack social confidence or worry about others trying to harm them. By learning more about our data-gathering and decision-making styles, we can become aware of problematic patterns and work towards a more helpful balance. This study seeks to understand the links between data-gathering style and degree of social confidence in people with and without ASC. We hope that insights gained from this work can help us adapt standard psychological therapies for people with ASC. Thank you for your contribution to this work.

Feeling worried about other people or social situations?

If you are somebody who feels anxious in social situations or someone who worries about other people talking badly about you or wanting to harm you - you are NOT alone. AND, there is help available.

Similarly, if you have felt upset about any of the questions you were asked as part of this study, the following websites can provide helpful further information and support as well as contact details for people you can talk to.

Social Anxiety UK **http://www.social-anxiety.org.uk/**

Social anxiety affects around 10% of people without ASC and around 40-50% of people with ASC at some point in their lives. You can find more information and support for social anxiety following the above link.

You can download a free self-help guide for social anxiety here:

http://www.moodjuice.scot.nhs.uk/shynesssocialphobia.asp

Samaritans **http://www.samaritans.org/**

Samaritans provides confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide.

UK: 08457 90 90 90 / ROI: 1850 60 90 90 Email: jo@samaritans.org

Sane **http://www.sane.org.uk/SANEline**

SANEline is a national out-of-hours telephone helpline offering emotional support and information for people affected by mental health problems.

Further questions or want to be informed about the findings?

If you have any further questions about the study, please contact Kristina Bennert at k.bennert@bath.ac.uk.

If you would like to be notified if this study is published in a scientific journal or you would like to receive a lay summary of the findings, please also contact Kristina Bennert at k.bennert@bath.ac.uk.

Demographic and Diagnostic Questions

About Yourself

1. Your age (enter in years)

2. Your gender (please tick)

☐ male ☐ female

☐ other ☐ prefer not to say

3. What is your highest educational qualification?

☐ None

☐ GSCEs or equivalent

☐ A-levels or equivalent

☐ University first degree (e.g. BA, BSc)

☐ Postgraduate qualification (e.g. MA, PhD)

☐ Other (please state)

☐ Prefer not to say

4. (a) Do you identify as having an autism spectrum condition? (This includes Asperger Syndrome, mild autism or high functioning autism.)

☐ yes ☐ no → go to Question 5.

↓ if yes

(b) Who gave you your autism spectrum diagnosis? (please tick <u>all</u> that apply)

☐ Self-diagnosed / friends and family

☐ School teacher /GP

☐ Paediatrician /Speech and Language Therapist

☐ Child Mental Health Service

☐ Specialist Child Autism Service

☐ Adult Mental Health Service

☐ Specialist Adult Autism Service

☐ Other (please state) _____

(c) <u>Roughly</u> at what age did you first get an autism spectrum diagnosis? (please tick one box only)

☐ Before age of 5 / preschool

☐ Age 5 -11 / during primary school

☐ Age 12-17 /during secondary school /college

☐ Age 18 or over

5. (a) Have you ever been diagnosed with mental health difficulties?

Yes No or Prefer not to say → go to question 6.

If yes ↓

(b) Please tell us which mental health difficulties you have been diagnosed with? (Please tick all that apply.)

☐ Depression

☐ Anxiety

☐ Social anxiety

☐ OCD

☐ Psychosis / schizophrenia

☐ Other

6. Are you <u>currently</u> experiencing any mental health difficulties?

Yes No or Prefer not to say → go to Part 1b (AQ10 + 4 and PDI Q1)

If yes ↓

Please tell us which mental health difficulties you are currently experiencing

☐ Depression

☐ Anxiety

☐ Social anxiety

☐ OCD

☐ Psychosis / schizophrenia

☐ Other (please state)

Clinical Outcome Measures

Autism Quotient Screening Instrument (AQ10) and AQ50 Systemising Factor (5 items)

Below are a list of statements. Please read each statement carefully and rate how strongly you agree or disagree with it by ticking the appropriate box.

1. I often notice small sounds when others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
2. I usually concentrate more on the whole picture, rather than the small details.	definitely agree	slightly agree	slightly disagree	definitely disagree
3. I find it easy to do more than one thing at once.	definitely agree	slightly agree	slightly disagree	definitely disagree
4. If there is an interruption, I can switch back to what I was doing very quickly.	definitely agree	slightly agree	slightly disagree	definitely disagree
5. When I'm reading a story, I find it difficult to work out the characters' intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
6. I find it easy to "read between the lines" when someone is talking to me.	definitely agree	slightly agree	slightly disagree	definitely disagree
7. I know how to tell if someone listening to me is getting bored.	definitely agree	slightly agree	slightly disagree	definitely disagree
8. I find it easy to work out what someone is thinking or feeling just by looking at their face.	definitely agree	slightly agree	slightly disagree	definitely disagree
9. I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).	definitely agree	slightly agree	slightly disagree	definitely disagree

10. I find it difficult to work out people's intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
11. I notice patterns in things all the time	definitely agree	slightly agree	slightly disagree	definitely disagree
12. I am fascinated by dates	definitely agree	slightly agree	slightly disagree	definitely disagree
13. I usually notice car number plates or similar strings of information	definitely agree	slightly agree	slightly disagree	definitely disagree
14. I am fascinated by numbers	definitely agree	slightly agree	slightly disagree	definitely disagree

Please read each of the statements carefully.

They refer to thoughts and feelings you may have had about others over the last month.

Think about the last month and indicate the extent of these feelings from 1 (Not at all) to 5 (Totally). Please complete both Part A and Part B.

(N.B. Please do not rate items according to any experiences you may have had under the influence of drugs.)

Part A		**Not at all**				**Totally**
1	I spent time thinking about friends gossiping about me	1	2	3	4	5
2	I often heard people referring to me	1	2	3	4	5
3	I have been upset by friends and colleagues judging me critically	1	2	3	4	5
4	People definitely laughed at me behind my back	1	2	3	4	5
5	I have been thinking a lot about people avoiding me	1	2	3	4	5
6	People have been dropping hints for me	1	2	3	4	5
7	I believed that certain people were not what they seemed	1	2	3	4	5
8	People talking about me behind my back upset me	1	2	3	4	5
9	I was convinced that people were singling me out	1	2	3	4	5
10	I was certain that people have followed me	1	2	3	4	5
11	Certain people were hostile towards me personally	1	2	3	4	5
12	People have been checking up on me	1	2	3	4	5
13	I was stressed out by people watching me	1	2	3	4	5
14	I was frustrated by people laughing at me	1	2	3	4	5
15	I was worried by people's undue interest in me	1	2	3	4	5
16	It was hard to stop thinking about people talking about me behind my back	1	2	3	4	5

Part B

1	Certain individuals have had it in for me	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
2	I have definitely been persecuted	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
3	People have intended me harm	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
4	People wanted me to feel threatened, so they stared at me	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
5	I was sure certain people did things in order to annoy me	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
6	I was convinced there was a conspiracy against me	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
7	I was sure someone wanted to hurt me	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
8	I was distressed by people wanting to harm me in some way	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
9	I was preoccupied with thoughts of people trying to upset me deliberately	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
10	I couldn't stop thinking about people wanting to confuse me	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
11	I was distressed by being persecuted	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
12	I was annoyed because others wanted to deliberately upset me	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
13	The thought that people were persecuting me played on my mind	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
14	It was difficult to stop thinking about people wanting to make me feel bad	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
15	People have been hostile towards me on purpose	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯
16	I was angry that someone wanted to hurt me	1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯

Social Interaction Anxiety Scale (SIAS)

For each item, please tick the box to indicate the degree to which you feel the statement is characteristic or true for you.

Characteristic of me….	**Not at all**	**Somewhat**	**Moderately**	**Very**	**Extremely**
1. I get nervous if I have to speak with someone in authority (teacher, boss, etc.).	0	1	2	3	4
2. I have difficulty making eye contact with others.	0	1	2	3	4
3. I become tense if I have to talk about myself or my feelings.	0	1	2	3	4
4. I find it difficult to mix comfortably with the people I work with.	0	1	2	3	4
5. I find it easy to make friends my own age.	0	1	2	3	4
6. I tense up if I meet an acquaintance in the street.	0	1	2	3	4
7. When mixing socially, I am uncomfortable.	0	1	2	3	4
8. I feel tense if I am alone with just one other person.	0	1	2	3	4
9. I am at ease meeting people at parties, etc.	0	1	2	3	4
10. I have difficulty talking with other people.	0	1	2	3	4
11. I find it easy to think of things to talk about.	0	1	2	3	4
12. I worry about expressing myself in case I appear awkward.	0	1	2	3	4
13. I find it difficult to disagree with another's point of view.	0	1	2	3	4
14. I have difficulty talking to attractive persons of the opposite sex.	0	1	2	3	4
15. I find myself worrying that I won't know what to say in social situations.	0	1	2	3	4
16. I am nervous mixing with people I don't know well.	0	1	2	3	4
17. I feel I'll say something embarrassing when talking.	0	1	2	3	4

18. When mixing in a group, I find myself worrying I will be ignored.	0	1	2	3	4
19. I am tense mixing in a group.	0	1	2	3	4
20. I am unsure whether to greet someone I know only slightly.	0	1	2	3	4

Peters Delusions Inventory (PDI) - Item for Persecutory Ideation

Do you ever feel as if you are being persecuted in some way?

(a) Yes No → go to next questionnaire

↓

(b) How distressing is this belief for you?

Not at all distressing 1 2 3 4 5 Very Distressing

(c) How often do you think about this belief?

Hardly ever think about it 1 2 3 4 5 Think about it all the time

(d) How true do you think this belief is?

I don't believe it's true 2 3 4 5 I believe it is absolutely true

Research Procedure Overview

Steps		Measures and materials
Recruitment		Study advert distributed via NAS mailing lists, autism online groups and social media
Consent 1: Information		Online Participant Information Sheet
Consent 2: Agreement		Electronic Consent Form: confirming all statements and clicking 'I agree' takes participants to the first questionnaire page
Part 1a	Participant details (no personally identifiable information)	Demographic data (age, gender, education) Information about autism and mental health diagnoses
Part 1b	Autism Screen to validate self-reported status	AQ10 + 4 questions from AQ50 'systemising factor' Item 4 from PDI with distress, frequency and conviction rating
Part 2	Experimental Task 1	Beads Task (randomised version A or B) or Survey Task (randomised version A or B)
Part 3	Questionnaires (52 items in total)	Social Interaction Anxiety Scale (20 items) Green Paranoid Thoughts Scale Part 1 (16 items) Green Paranoid Thoughts Scale Part 2 (16 items)
Part 4	Experimental Task 2	Beads Task (randomised version A or B) or Survey Task (randomised version A or B)
Part 5	Feedback on tasks	How did you find the beads task / survey task? [Analogue scale from distressing over neutral to enjoyable Is there anything else you would like to tell us about your experience of completing: the beads task? [open comment] the survey task? [open comment]
Debrief		Electronic debrief sheet with support agency info (to print off if needed) and researcher contact details

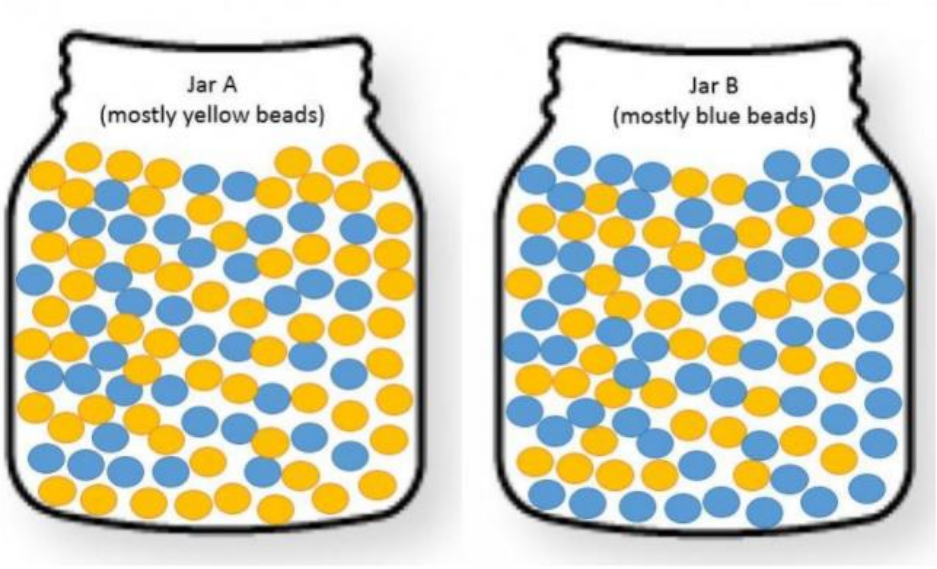
Task Design

Beads Task Instructions

In this task, you will be asked to decide from which of two jars a series of beads is being drawn.

Below are two jars of beads. Jar A on the left contains 60 yellow beads and 40 blue beads and Jar B on the right contains 40 yellow beads and 60 blue beads.

The computer will randomly select one of the two jars, A or B. The computer will then randomly draw a bead from the chosen jar and let you know if the bead is yellow or blue. The bead will then be returned to the jar.



Your task is to decide whether the beads are drawn from Jar A (mostly yellow beads) or Jar B (mostly blue beads).

After each time a bead is shown to you, you have the choice to either:

1.) **Decide** which jar the beads are drawn from, or

2.) Ask to **See another bead** from the jar.

Click on **Decide** if you feel you have seen enough beads to make a decision about which jar they come from. You will be taken to a screen to record your choice (i.e. Jar A or Jar B).

Click on **See another word** if you want to computer to show you more beads from the selected jar before you make up your mind.

You can keep requesting more beads until you are ready to make a decision.

Please click the next button when you are ready to begin. You will not be able to return to these instructions once you have started the task.

Order of Beads (based on Dudley et al. 1997, 60:40 ratio version)

Blue Condition: B Y Y B B Y B B B Y B B B B Y Y B Y Y B

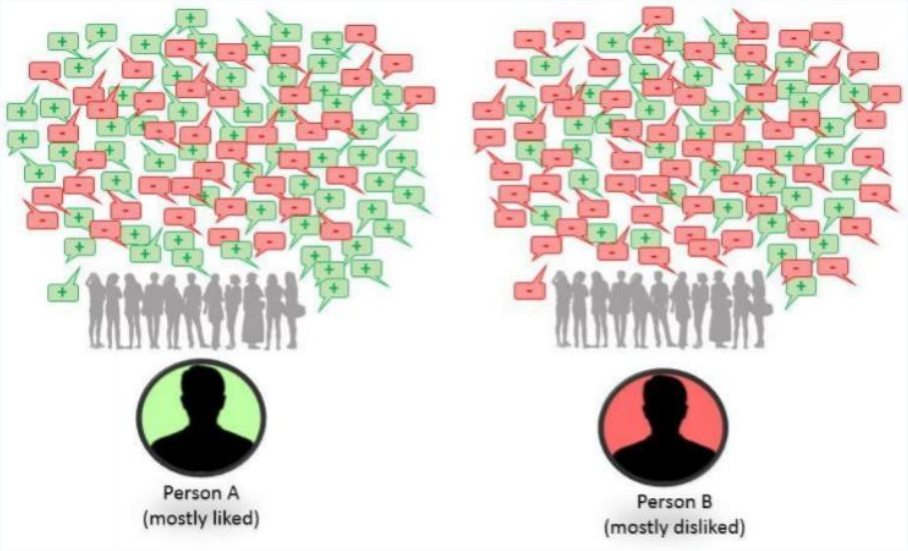
Yellow Condition: Y B B Y Y B Y Y Y B Y Y Y Y B B Y B B Y

Survey Task Instructions

In this task, you will be asked to decide which of two individuals – Person A or Person B – is being described by a group of their friends and acquaintances.

Person A is mostly liked. From a survey among 100 people who know Person A, 60 people described that person using positive words, while only 40 people described that person using negative words.

Person B is mostly disliked. From a survey among 100 people who know Person B, 60 people described that person using negative words, while only 40 people described that person using positive words.



The computer will randomly select either the survey describing Person A (mostly liked) or the survey describing Person B (mostly disliked). You will then be shown one word at a time taken at random from that survey only. After the word has been shown to you, it will be returned to the survey.

Your task is to decide whether the selected survey is the one describing Person A or Person B.

After each word, you have the choice to either:

1.) **Decide** which person is being described in the survey, or

2.) Ask to **See another word** from the survey.

Click on **Decide** if you feel you have seen enough words to make a decision about which person is being described. You will be taken to a screen to record your choice (i.e. Person A or Person B).

Click on **See another word** if you want to computer to show you more words from the survey before you make up your mind.

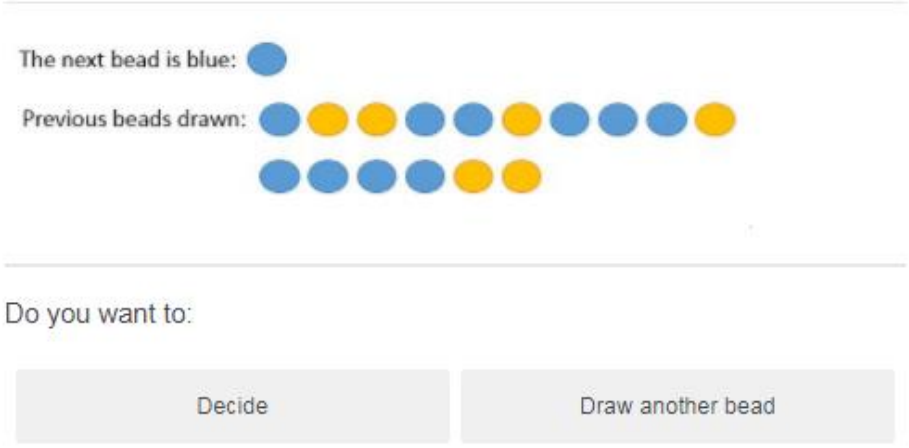
You can keep requesting more words until you are ready to make a decision.

Please click the next button when you are ready to begin. You will not be able to return to these instructions once you have started the task.

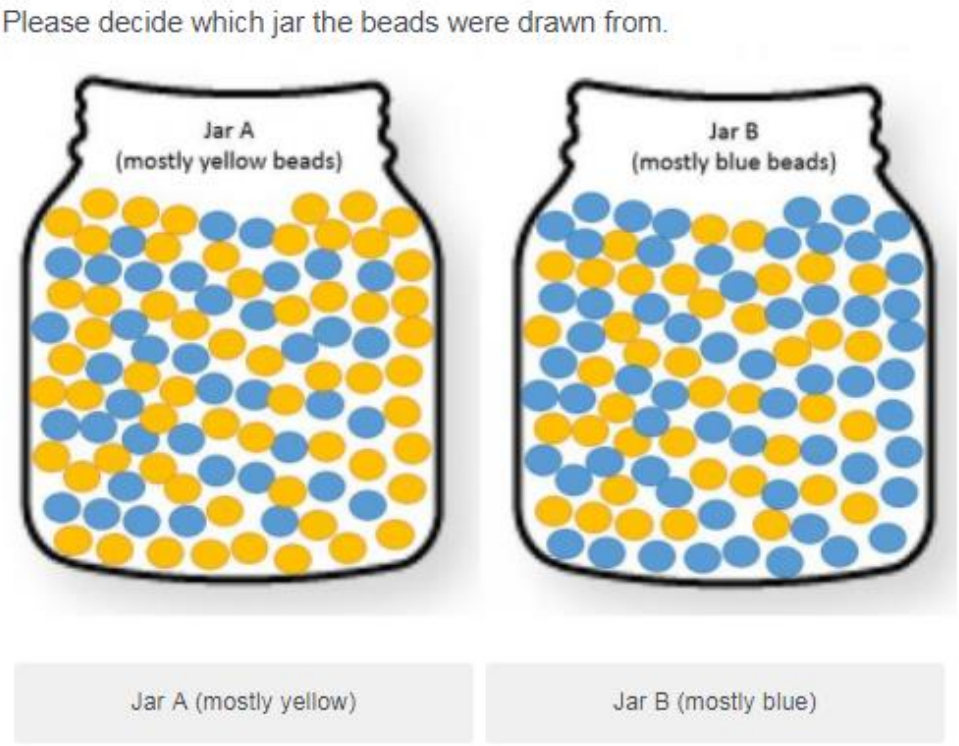
Order of Words for Survey Task (based on Dudley et al. 1997)

Positive Traits Condition	Negative Traits List
1) generous	1) annoying
2) annoying	2) generous
3) unreliable	3) cheerful
4) cheerful	4) unreliable
5) kind	5) offensive
6) offensive	6) kind
7) amusing	7) selfish
8) bright	8) inconsiderate
9) honest	9) envious
10) selfish	10) amusing
11) wise	11) cold-hearted
12) gentle	12) pessimistic
13) considerate	13) mean
14) helpful	14) dishonest
15) envious	15) bright
16) pessimistic	16) wise
17) polite	17) rude
18) mean	18) helpful
19) cold-hearted	19) gentle
20) friendly	20) unfriendly

Screenshot: Decide or Continue – Beads Task

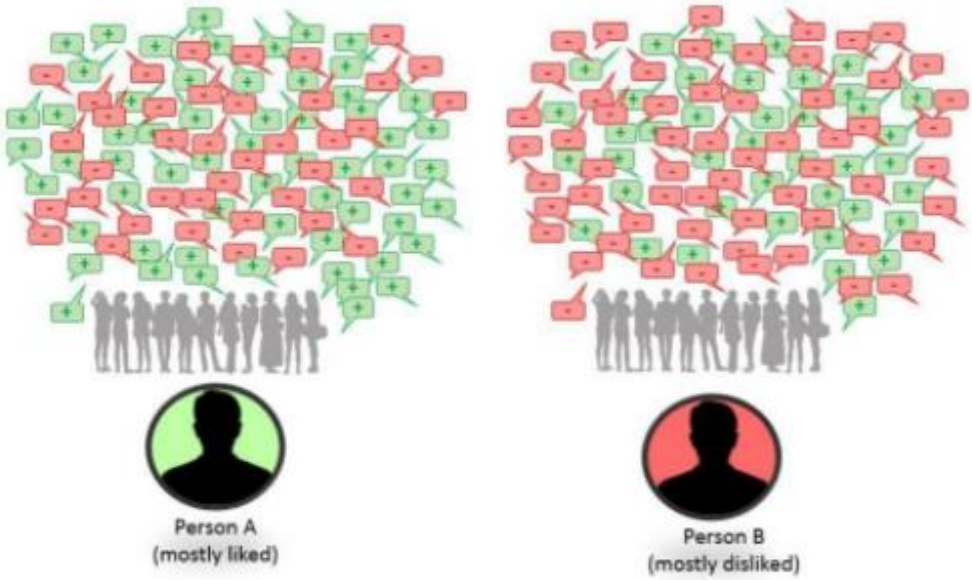


Screenshot: Deice and Rate Confidence –Beads Task



Screenshot: Decide and Rate Confidence –Survey Task

Please decide which person is being described in the survey.



Person A (mostly liked) | Person B (mostly disliked)

How confident are you in your decision? Please move the slider below to indicate your level of confidence.

Click on the 'next' button below when you are done.

0 10 20 30 40 50 60 70 80 90 100

% confident

<< Next

Screenshot: Halfway Message

You're halfway through!

Next up are a few more questions about your social confidence and about fearful thoughts about others that some people might experience.

Remember, all responses in this survey are anonymised and cannot be traced back to the individuals taking part.

After these questions, you will be asked to complete another short decision-making task, and then you're done. Afterwards, you will be able to find out further information about these tasks and what we are hoping to achieve with the findings from this study.

<< Next

Screenshot: Rating of Task Enjoyment and Feedback Invitation

We are interested to know whether there are differences in how people experience the two tasks in this experiment.

Please rate your experience of the decision-making task involving words from a survey:

 **unpleasant** **enjoyable** 

-10 -8 -6 -4 -2 0 2 4 6 8 10

I found doing the task...

Please rate your experience of the decision-making task involving beads from a jar:

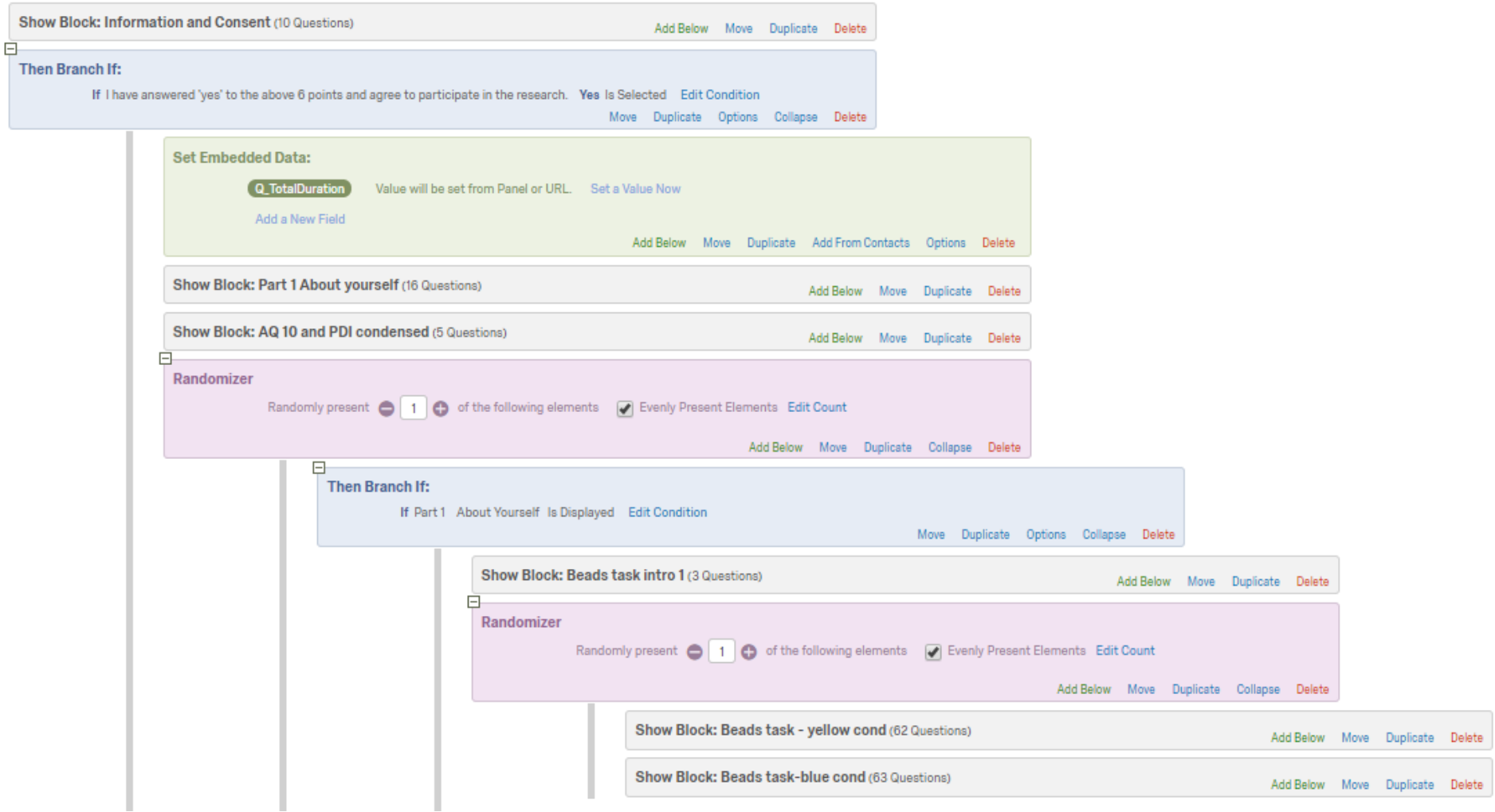
 **unpleasant** **enjoyable** 

-10 -8 -6 -4 -2 0 2 4 6 8 10

I found doing the task...

Is there anything else you would like to tell us about your experience of completing the two tasks?

Survey Flow


Show Block: Information and Consent (10 Questions)
Add Below Move Duplicate Delete
Then Branch If:
If I have answered 'yes' to the above 6 points and agree to participate in the research. Yes Is Selected Edit Condition
Move Duplicate Options Collapse Delete
Set Embedded Data:
Q_TotalDuration Value will be set from Panel or URL. Set a Value Now
Add a New Field
Add Below Move Duplicate Add From Contacts Options Delete
Show Block: Part 1 About yourself (16 Questions)
Add Below Move Duplicate Delete
Show Block: AQ 10 and PDI condensed (5 Questions)
Add Below Move Duplicate Delete
Randomizer
Randomly present 1 of the following elements Evenly Present Elements Edit Count
Add Below Move Duplicate Collapse Delete
Then Branch If:
If Part 1 About Yourself Is Displayed Edit Condition
Move Duplicate Options Collapse Delete
Show Block: Beads task intro 1 (3 Questions)
Add Below Move Duplicate Delete
Randomizer
Randomly present 1 of the following elements Evenly Present Elements Edit Count
Add Below Move Duplicate Collapse Delete
Show Block: Beads task - yellow cond (62 Questions)
Add Below Move Duplicate Delete
Show Block: Beads task-blue cond (63 Questions)
Add Below Move Duplicate Delete

Show Block: half way message (1 Question) Add Below Move Duplicate Delete

Show Block: Part 3 SIAS condensed (3 Questions) Add Below Move Duplicate Delete

Show Block: PART 3 GPTS condensed (4 Questions) Add Below Move Duplicate Delete

Show Block: Survey task - intro (3 Questions) Add Below Move Duplicate Delete

Randomizer

Randomly present 1 of the following elements Evenly Present Elements Edit Count

Add Below Move Duplicate Collapse Delete

Show Block: Survey task-positive traits cond (62 Questions) Add Below Move Duplicate Delete

Show Block: Survey task - negative traits cond new (62 Questions) Add Below Move Duplicate Delete

+ Add a New Element Here

+ Add a New Element Here

Then Branch If:

If Part 1 About Yourself Is Displayed Edit Condition

Move Duplicate Options Collapse Delete

Show Block: Survey task - intro (3 Questions) Add Below Move Duplicate Delete

Randomizer

Randomly present 1 of the following elements Evenly Present Elements Edit Count

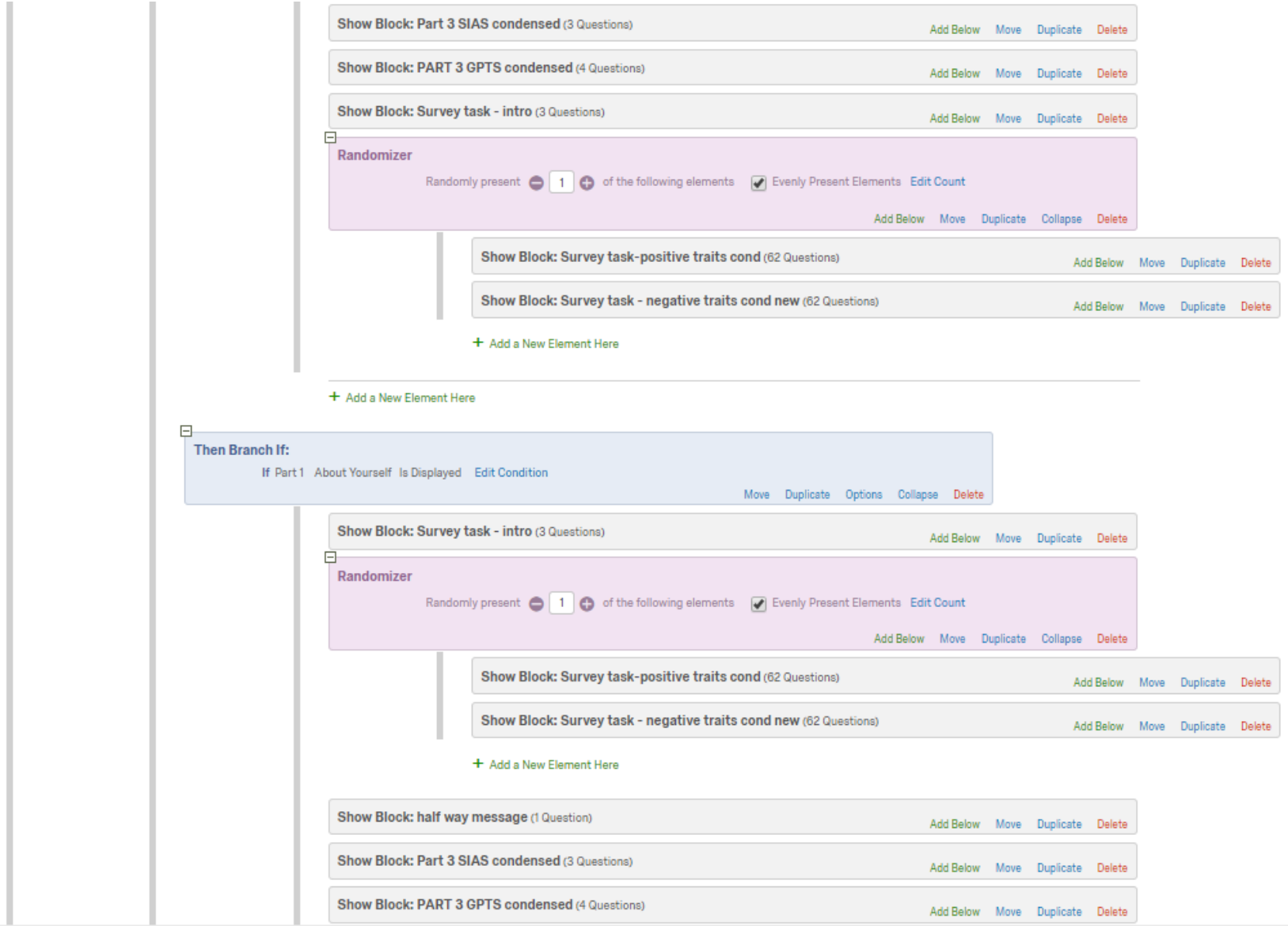
Add Below Move Duplicate Collapse Delete

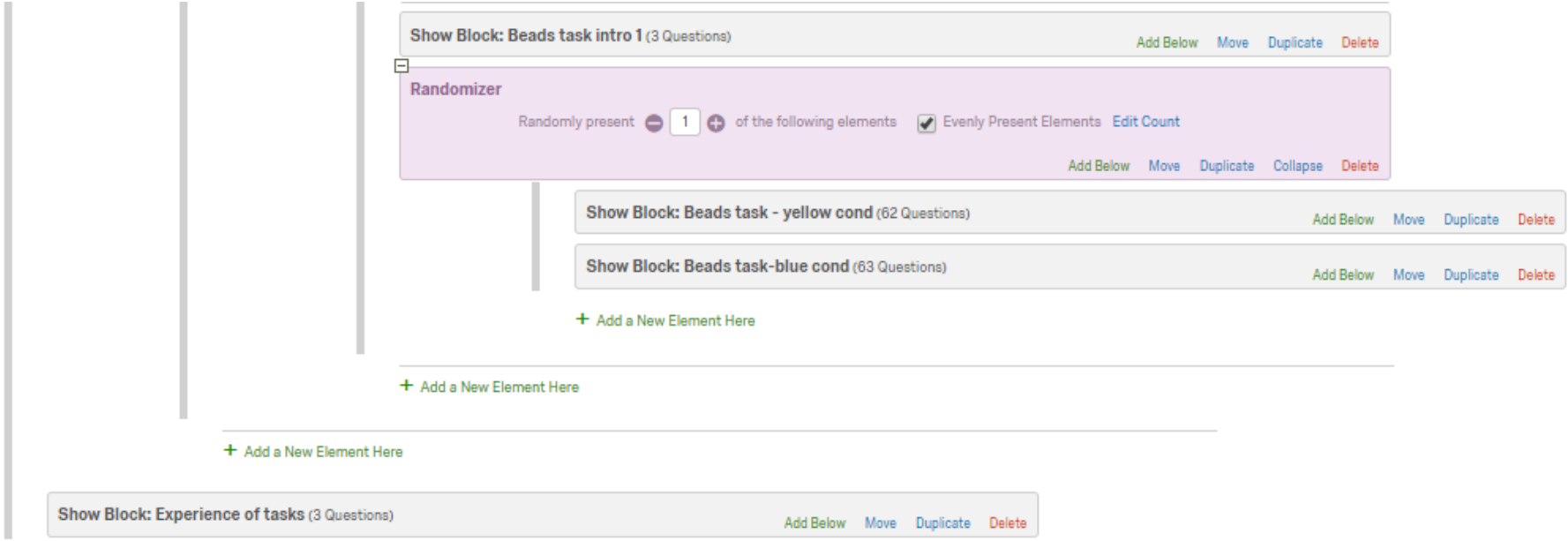
Show Block: Survey task-positive traits cond (62 Questions) Add Below Move Duplicate Delete

Show Block: Survey task - negative traits cond new (62 Questions) Add Below Move Duplicate Delete

+ Add a New Element Here

Show Block: half way message (1 Question) Add Below Move Duplicate Delete


Show Block: Part 3 SIAS condensed (3 Questions) Add Below Move Duplicate Delete
Show Block: PART 3 GPTS condensed (4 Questions) Add Below Move Duplicate Delete
Show Block: Survey task - intro (3 Questions) Add Below Move Duplicate Delete
Randomizer
Randomly present 1 of the following elements Evenly Present Elements Edit Count
Add Below Move Duplicate Collapse Delete
Show Block: Survey task-positive traits cond (62 Questions) Add Below Move Duplicate Delete
Show Block: Survey task - negative traits cond new (62 Questions) Add Below Move Duplicate Delete
Add a New Element Here
Add a New Element Here
Then Branch If:
If Part 1 About Yourself Is Displayed Edit Condition
Move Duplicate Options Collapse Delete
Show Block: Survey task - intro (3 Questions) Add Below Move Duplicate Delete
Randomizer
Randomly present 1 of the following elements Evenly Present Elements Edit Count
Add Below Move Duplicate Collapse Delete
Show Block: Survey task-positive traits cond (62 Questions) Add Below Move Duplicate Delete
Show Block: Survey task - negative traits cond new (62 Questions) Add Below Move Duplicate Delete
Add a New Element Here
Show Block: half way message (1 Question) Add Below Move Duplicate Delete
Show Block: Part 3 SIAS condensed (3 Questions) Add Below Move Duplicate Delete
Show Block: PART 3 GPTS condensed (4 Questions) Add Below Move Duplicate Delete



Debrief Information

Participant Feedback on Taking Part

TD Group Comments

Is there anything else you would like to tell us about your experience of completing the two tasks?

1. *A bit anxious*
2. *It was a guess based on probability - I could not be certain because the comment/ bead may have been from the other jar/ survey.*
3. *They were basically the same task, presented differently*
4. *They were the same task - one was about people, the other about beads but the task was exactly the same logic.*
5. *For me it was a question of mathematical probability and level of certainty rather than a guessing game and level of confidence*
6. *I felt more confident in the beads jar because i had had experience of doing the one before and also because it was more visual - the colours of the beads matched so it made me more certain whereas the adjectives i needed to interpret and then group, it wasn't as easy as just looking at the matching colours and 'knowing'.*
7. *The bead task is harder to give an answer to as there are only 2 colours of beads whereas the words used to describe the people are all different and can be connective therefore a decision is easier to make*
8. *Making a decision based on colour was easier, because no interpretation was needed in the way it was for the words. The colours were just there: bam. In both cases I drew ten words/beads to ensure a statistically representative sample.*
9. *I essentially ended up guessing as it would take a long time to have enough beads/words to be certain.*
10. *For the task of relating descriptive words to people who are 'mostly liked' or 'mostly disliked', I think that it is not really possible to choose as there is no way of truly knowing. Just because people find somebody annoying at times, it doesn't mean that they dislike them or vice versa.*

11. *There was more doubt with the second task in my opinion, as the word when first shown seemed negative, however it could have easily been used for the positive person, by the 40% who were negative about that person. / / The objects in a container were based more on facts and probabilities.*
12. *It is only on new surroundings and among new people places*
13. *N/A*
14. *Confused about what they are designed to find out*

ASC Group Comments

1. *No*
2. *I'm not sure if I chose the correct education option. I am Canadian and completed a university streamed high school program and 3 out of 4 years of an Bachelors in education*
3. *In the second test I thought that there was no indication: i.e. the jars contained the same number after extraction...*
4. *They felt identical to me*
5. *I approached both tasks the same way. I asked for 5 examples, then picked the person/jar based on which one got three or more — that is 60% — of the of the appropriate elements. / / The first task had a complication since I had to first classify if a word was positive or negative, which required additional knowledge or vocabulary, word connotations and what's generally considered a positive or negative trait. By contrast, distinguishing between blue and yellow was much more straightforward and required no additional knowledge. / / Beyond that, though, the two tasks were essentially interchangeable. /*
6. *It seemed that page load times in the bread task were longer (possibly due to loading images farther than words), which made it less enjoyable. Might be an effect of my network connection.*
7. *i dont like the thought of people thinking or talking bad about each other*

8. *Perhaps judged the word one too quickly as annoying can be used in a positive way on occasion but I took it literally as negative.*

1. *It's fairly obviously a binomial distribution (well, actually only approximately binomial since you are not replacing the token each time but the numbers are large enough for the approximation to be quite good, I think) / 2. Maximising the sample size is the obvious strategy for obtaining the best estimate of the probability. / 3. Once I'd realised the nature of the problem the social meaning of the first task disappeared for me; I found deriving the best estimate of P more interesting than thinking about feelings and words.*

9. *Exactly the same = simply a matter of mathematical probability.*

10. *Very frustrating to have to click "show me one more" again and again. Maybe "show all" should be an option for people like me who want to take a rational approach?*

11. *No.*

12. *Confused*

13. *Words was harder because you can't just look and see it, you had to count good and bad*

14. *N/a*

15. *I did not understand the first one at all and found it confusing. / / The second one I did understand, but I could not click on anything and did not like the fact that it was not fast enough.*

16. *Beads from the jar could be done by counting. I counted 40 blue remaining in the left-hand jar, so (unless I miscounted!) the blue bead must have been removed from the right-hand jar. / / Unless I didn't read the rubric carefully enough, the words problem was could only be done by probabilities. Since "generous" seems to be a positive word, the probability was 60% that it was used to describe the more popular person. (If I got my figures right!)*

17. *I did not understand the instructions on the jellybean task. I thought I was supposed to be comparing a before and after picture that would only change by 1 jellybean at a time. I have difficulty with written instructions alone without seeing*

a task done then mimicking it and take longer than most people to understand. It wasn't until the 2nd task that I figured out what to do. Draw 10 items, seperate the words into two categories (positive and negative) and add up each category and mutliply by 10 to see which person is being described.

18. *They struck me as very similar.*
19. *I find it confusing when you first asked something like "do you think you have been prosecuted?" I was bullied in middle school but I don't think people around me now are trying to prosecute me. So all my answers under that (15a I believe?) are about my feelings towards the bullying in middle school instead of feelings about being prosecuted now. Thanks.*
20. *much harder to do second task, having to read the list each time and count the positive words vs the negative words. Much easier with colours in first task. If the intention was that I would be able to create a virtual persona based on all the qualities of the words given, that was not possible because they were conflicting, it was only possible to do it mathematically.*
21. *I found the task about words describing people harder as it is more ambiguous.*

Appendix 2: SPSS Outputs from Statistical Analysis

POWER CALCULATIONS

CHECKS FOR RANDOMISATION ACROSS SAMPLES

PRELIMINARY TESTS AND CHECKS FOR BIASES IN THE DATA

Histograms and Frequency Table

- Autism Quotient Screening Tool (AQ10 Scores).
- Autism Quotient Systemising Factors (AQ50- 5 Items).
- Paranoia (GPTS Scores).
- Social Anxiety (SIAS Scores).

Checks for Outliers: P-P plots and Boxplots

Table with standardised scores for skew and kurtosis in the distribution of clinical measures

Tests for Normality for Distribution of Scores on Continuous Variables: Kolmogorov-Smirnov Test and Q-Q Plots

Tests of Homogeneity of Variance on Scores Between Groups: Levene's Test

BETWEEN-GROUP COMPARISONS FOR CLINICAL MEASURES

Paranoia scores (GPTS)

Social Anxiety Scores (SIAS)

PLANNED COMPARISONS ON TASK PERFORMANCE VARIABLES

HYPOTHESIS 1: SPSS OUTPUT

Mann Witney U Test for Draws to Decision on the Beads Task for ASC and TD Groups

Mann Witney U Test for Draws to Decision on the Survey Task for ASC and TD Groups

HYPOTHESIS 2: SPSS OUTPUT

Chi Square for Autism * JTC bias

HYPOTHESIS 3: SPSS OUTPUT

Wilcoxon Singed Rank Test for Within Group Comparison of Task Performance between the two task versions: output for TD group and ASC group

HYPOTHESIS 4: SPSS OUTPUT

Spearman's Bivariate Correlation, one-tailed, for Paranoia and Draws to Decision

HYPOTHESIS 5: SPSS OUTPUT

Spearman's Bivariate Correlation, one-tailed, for Systemising and Draws to Decision

SPSS OUTPUT FOR POSTHOC EXPLORATION OF TASK PERFORMANCE VARIABLES

Mann Witney U Test for Confidence at Decision Beads Task and Survey Task

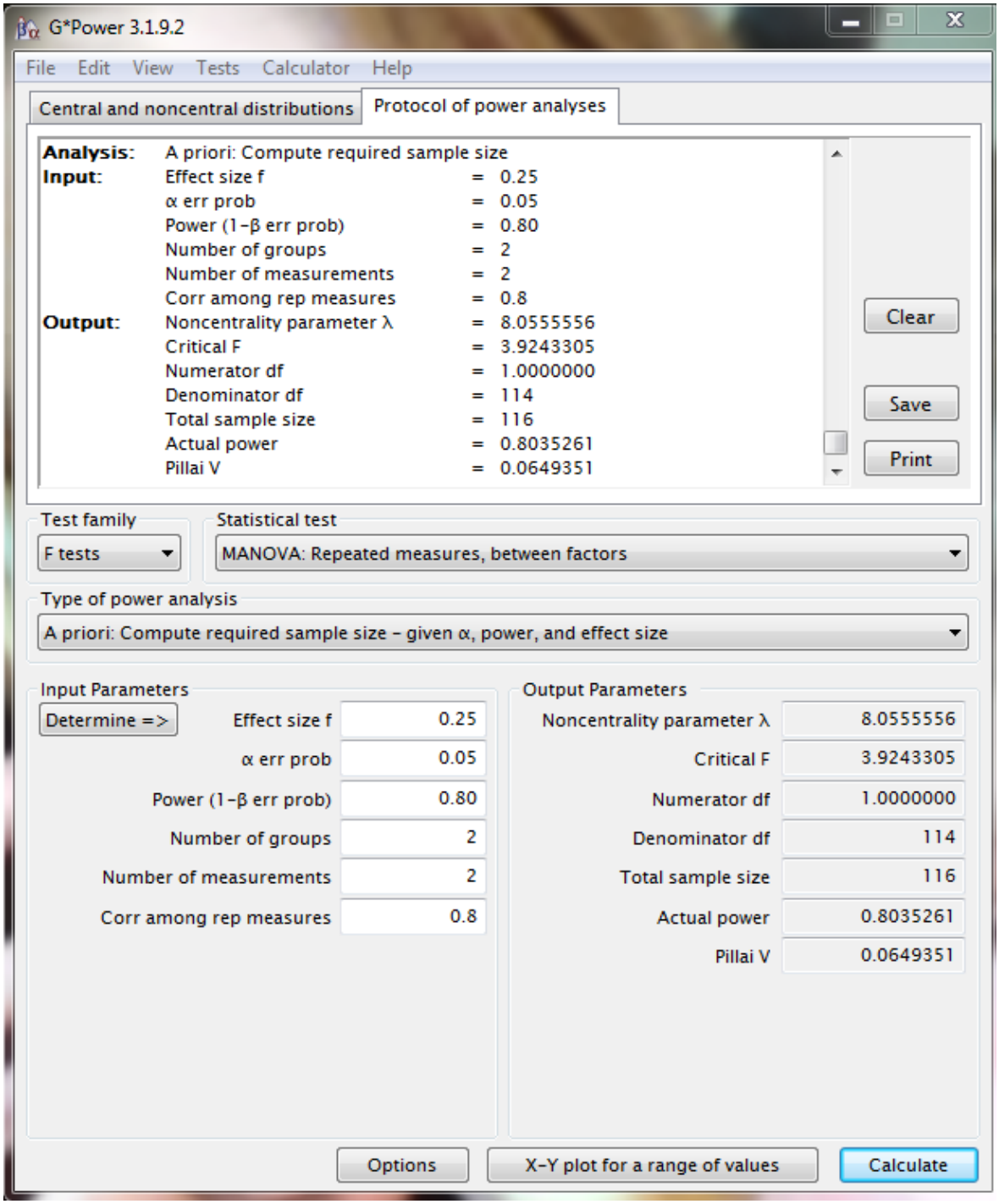
Mann Witney U Test for Completion Time: Beads Task and Survey Task

Chi Square Tests for Correct vs Incorrect Choice of Jar /Survey by Group

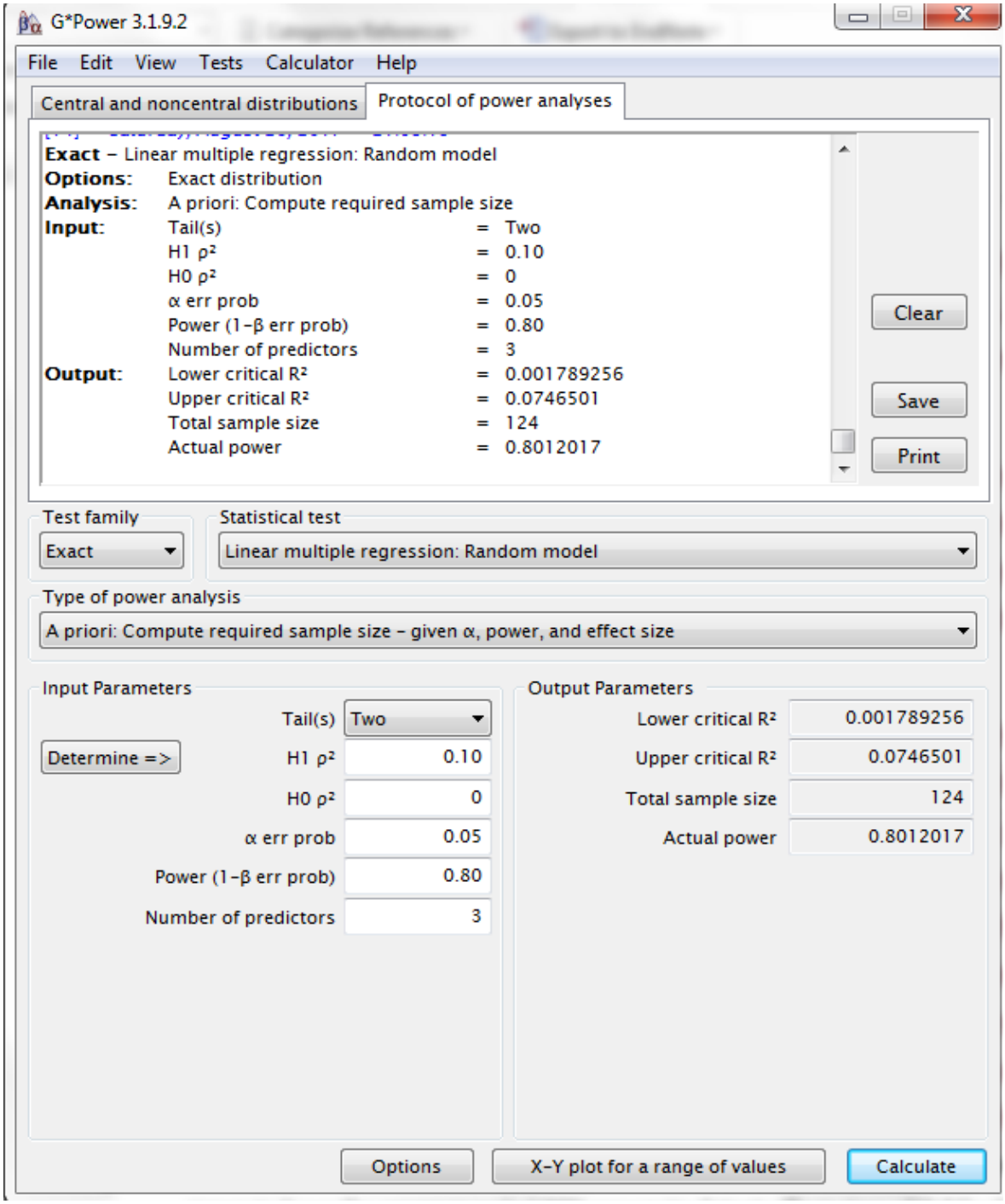
Chi Square Test for Presence of Persecutory Ideation (single item from PDI)

Power Calculations

Power calculation for original main research hypothesis: MANOVA (for MANCOVA)



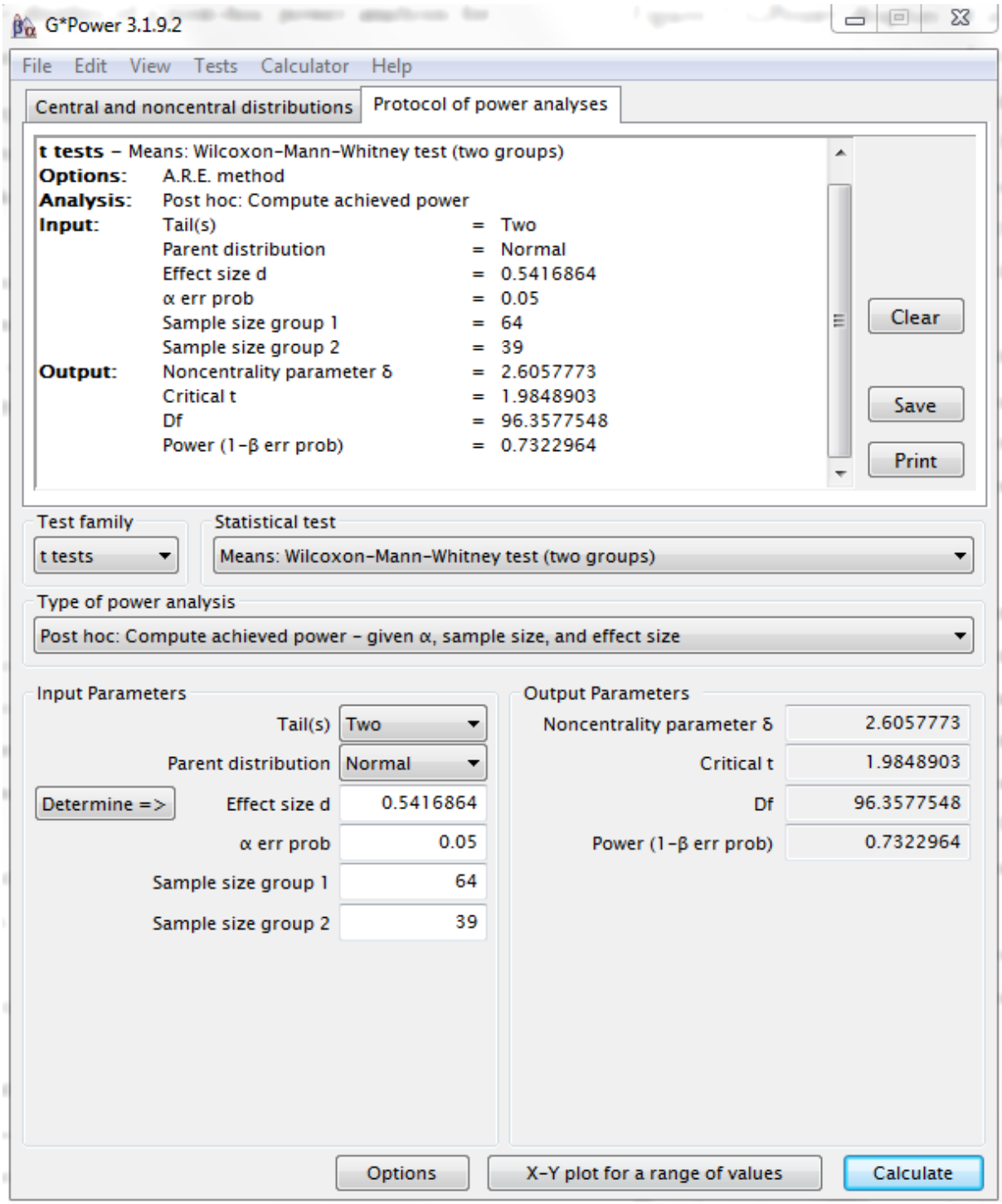
Power Calculation for Multiple Regression with Three Predictors



Power Calculations for Revised Analysis Plan

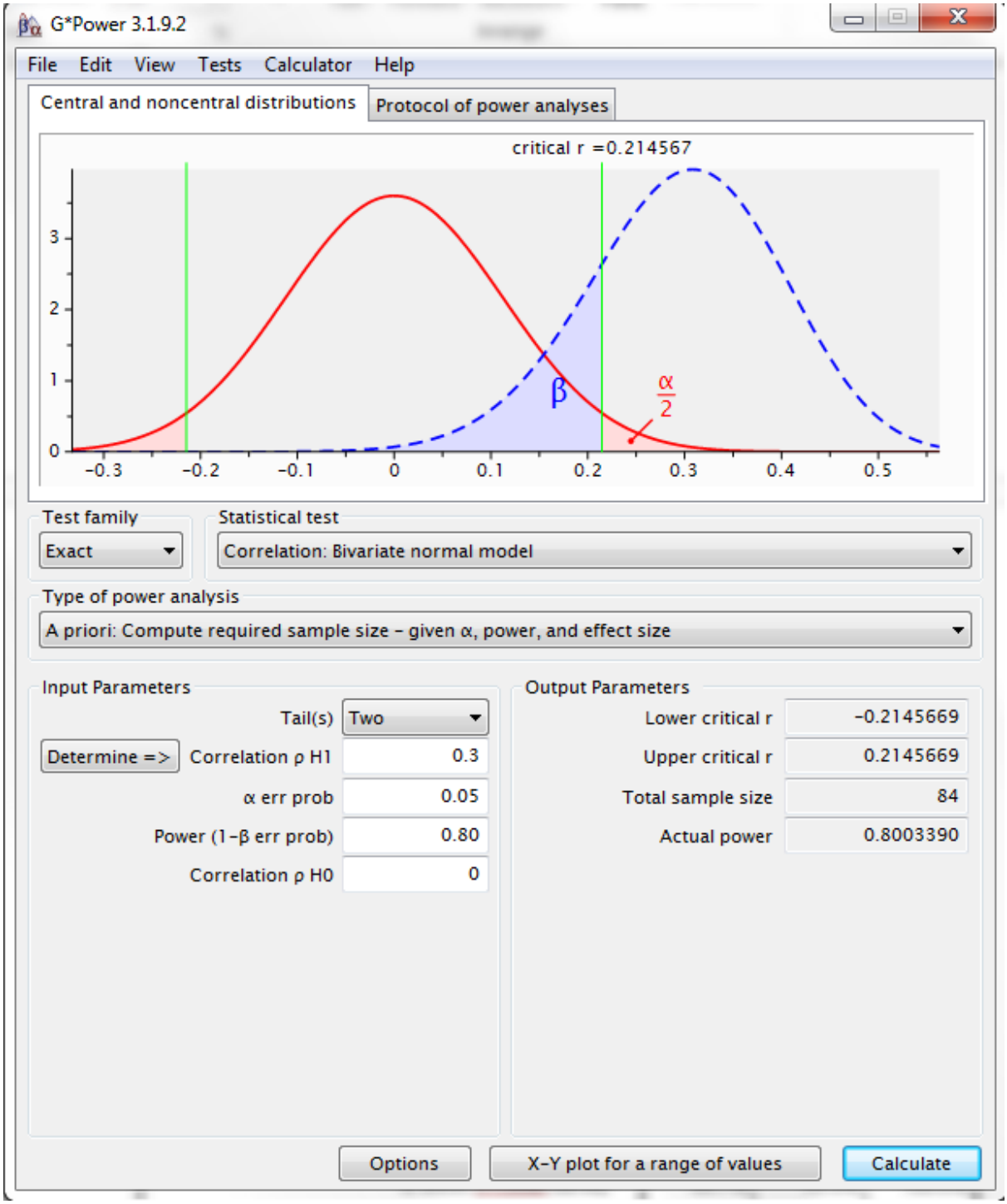
Posthoc power calculation

Main comparison: draws to decision (Mann Witney U test):



A priori power calculation for bivariate correlation (Paranoia and Draws to decision)

To detect a small to medium effect size (=>0.3), 84 cases are required (in each group) for a two-tailed hypothesis. For a medium effect size (=0.5), 29 in each group and for a large effect size (=0.7) 13 in each group.



task version beads * autism Crosstabulation

Count

		autism		
		no	yes	Total
task version beads	blue	37	26	63
	yellow	36	27	63
Total		73	53	126

task version survey * autism Crosstabulation

Count

		autism		
		no	yes	Total
task version survey	negative traits	39	24	63
	positive traits	34	29	63
Total		73	53	126

task order * autism Crosstabulation

Count

		autism		
		no	yes	Total
task order	survey first	33	29	62
	beads first	40	24	64
Total		73	53	126

Histograms and Frequency Table

Autism Quotient Screening Tool (AQ10 Scores).

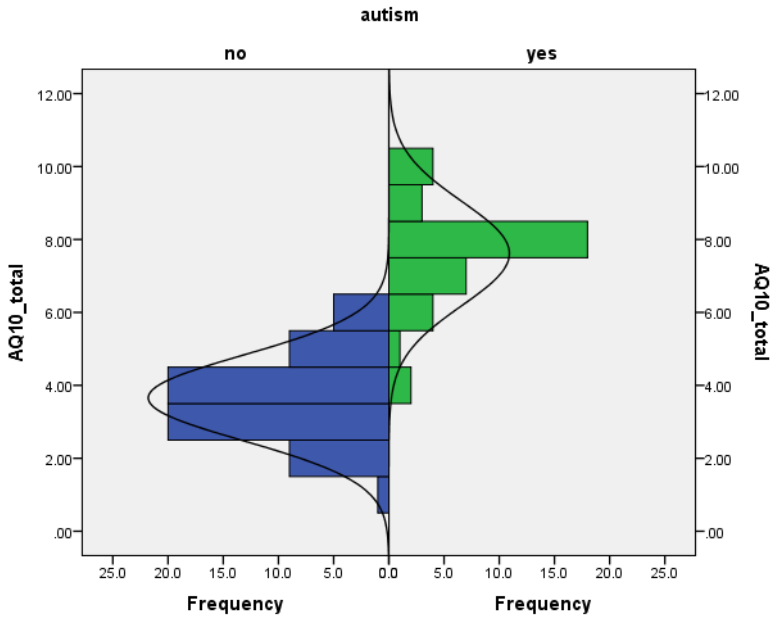


Figure: Distribution of AQ10 Scores for TD and ASC Group

Autism Quotient Systemising Factors (AQ50- 5 Items).

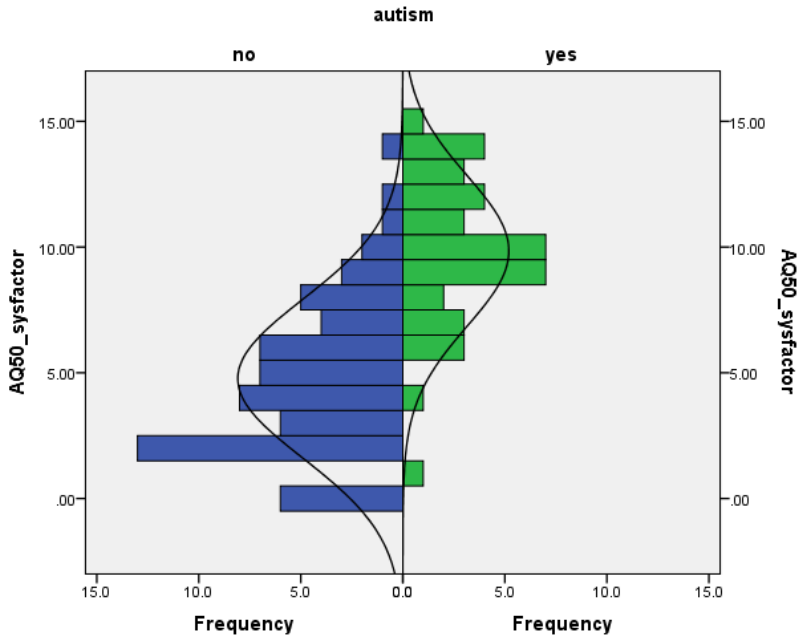


Figure: Distribution of AQ50 Systemising Factor Scores for TD and ASC Group

Paranoia (GPTS Scores).

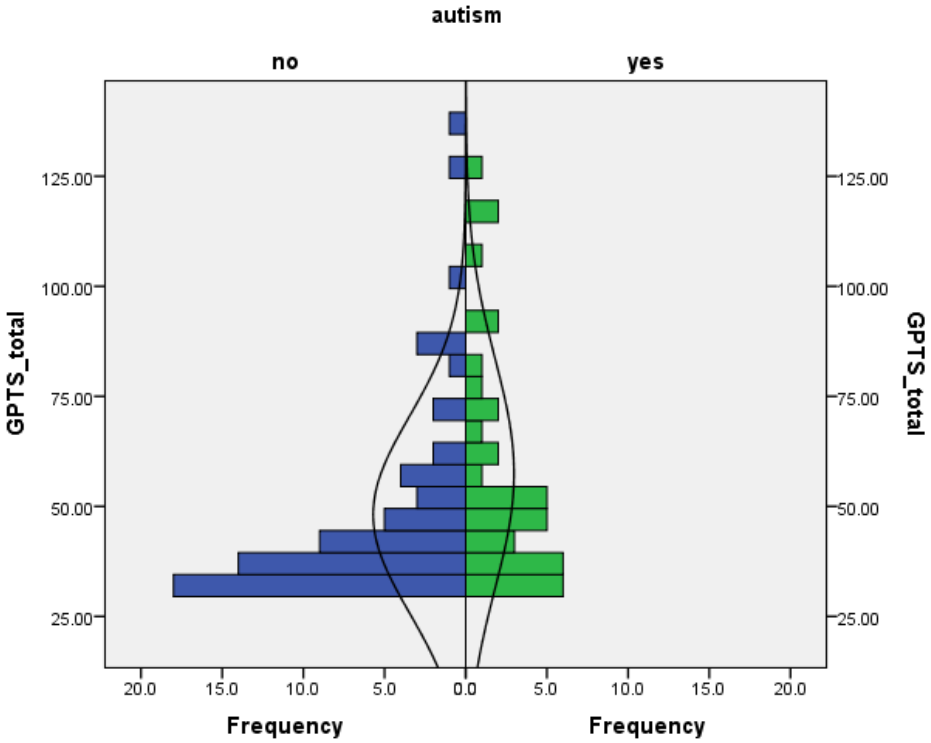


Figure: Distribution of GPTS Scores for TD and ASC Group

Social Anxiety (SIAS Scores).

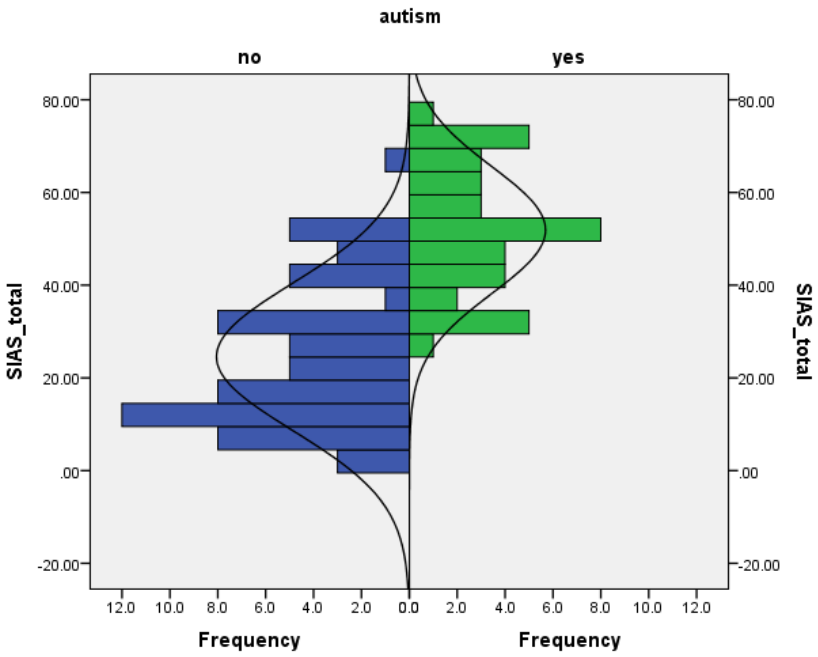


Figure: Distribution of GPTS Scores for TD and ASC Group

Table: Summary of Standardised Scores for Skew and Kurtosis in Clinical Measures Scores

	z_S	z_S	z_S	z_S
AQ10 screen	0.742	-0.593	-1.714	1.224
AQ50-factor	2.074*	0.202	-1.601	1.009
GPTS	7.428***	8.746***	3.458**	1.109
SIAS	2.231*	-0.639	0.090	1.281

Checks for Outliers: P-P plots and Boxplots

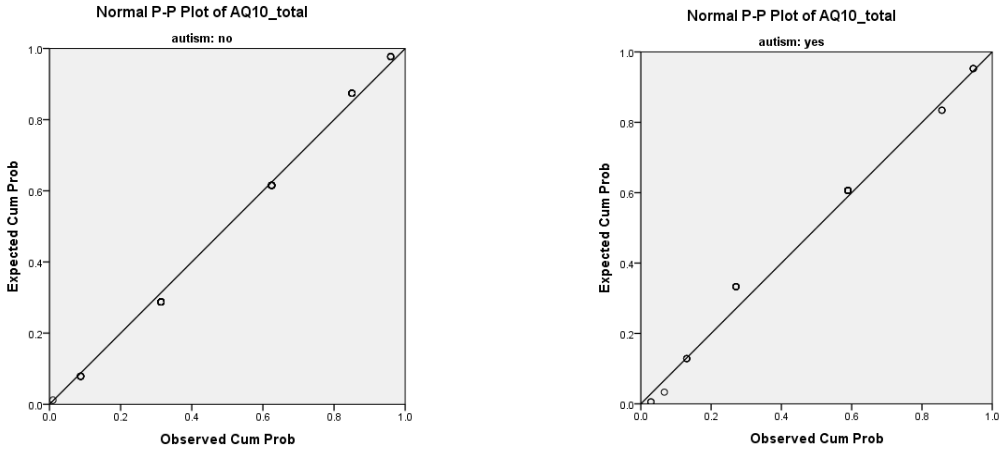


Figure: P-P Plots for AQ10 – TD group and ASC Group

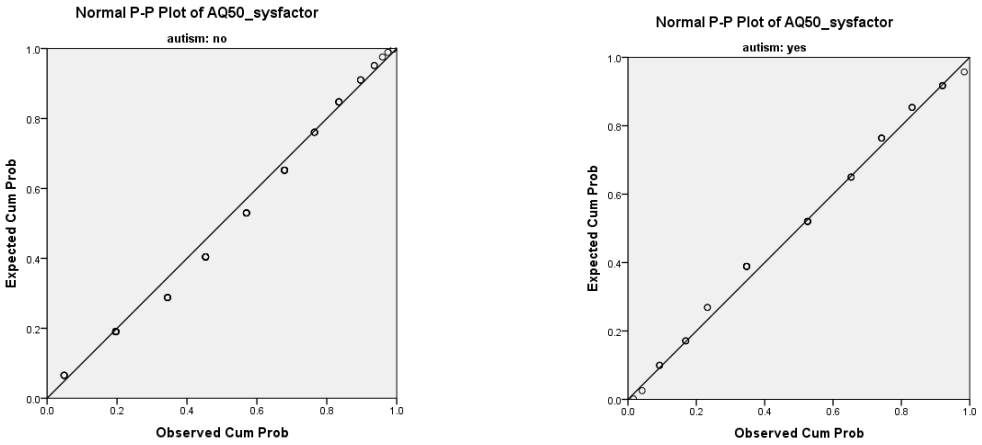


Figure: P-P Plots for AQ50- Systemising Factor – TD Group and ASC Group

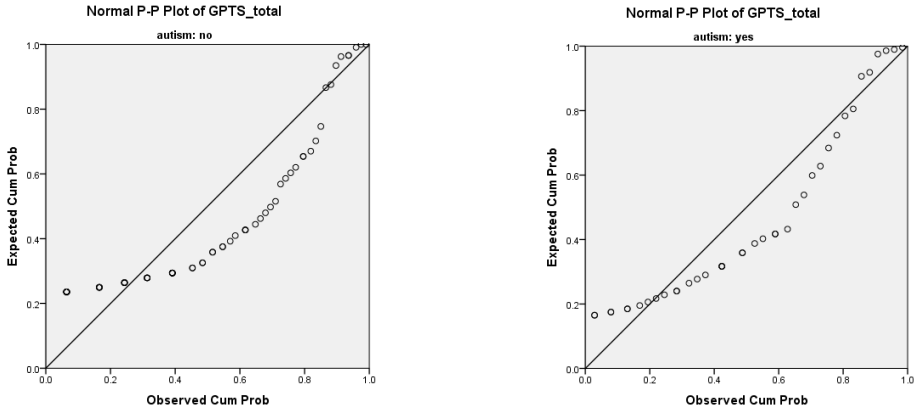


Figure: P-P Plots for GPTS – TD group and ASC Group

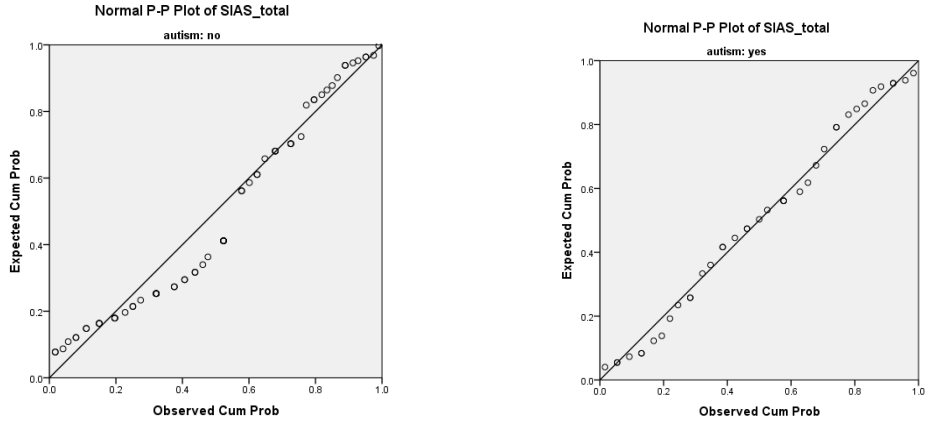


Figure: P-P Plots for SIAS – TD group and ASC Group

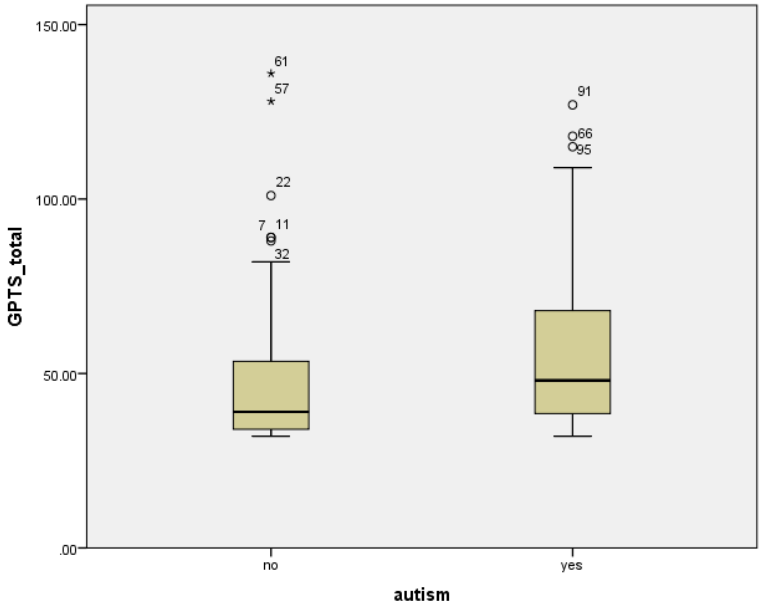


Figure: Boxplots for GPTS – TD group and ASC Group

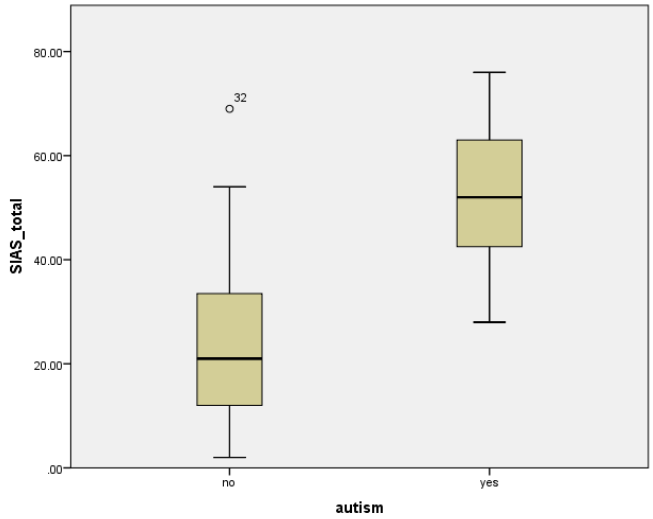


Figure: Boxplots for SIAS – TD group and ASC Group

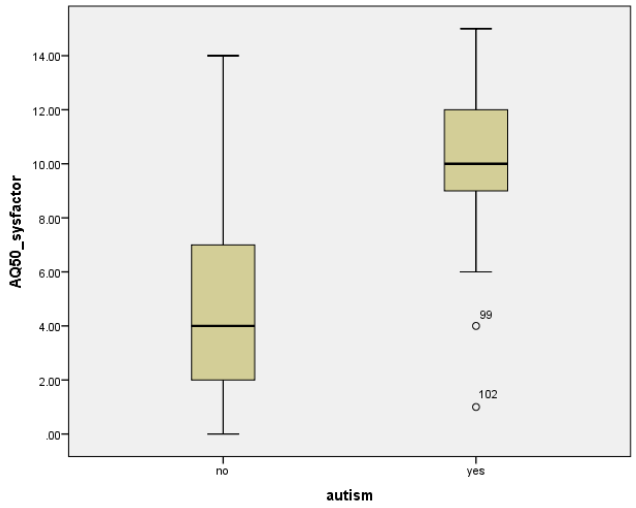


Figure: Boxplots for AQ50 – TD group and ASC Group

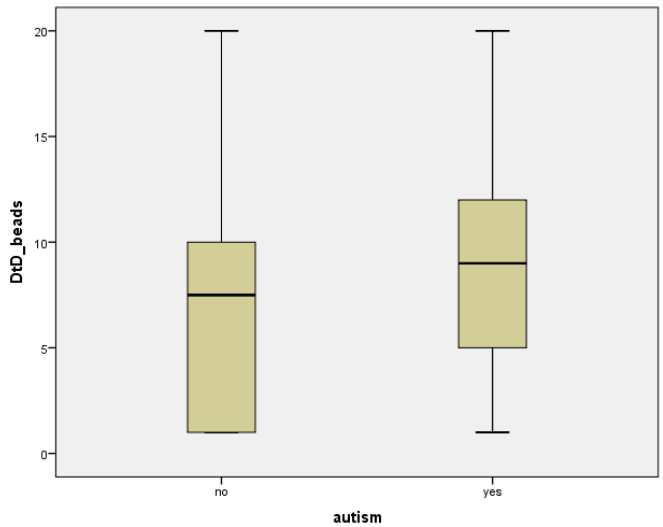


Figure: Boxplots for Draws to Decision Beads Task– TD group and ASC Group

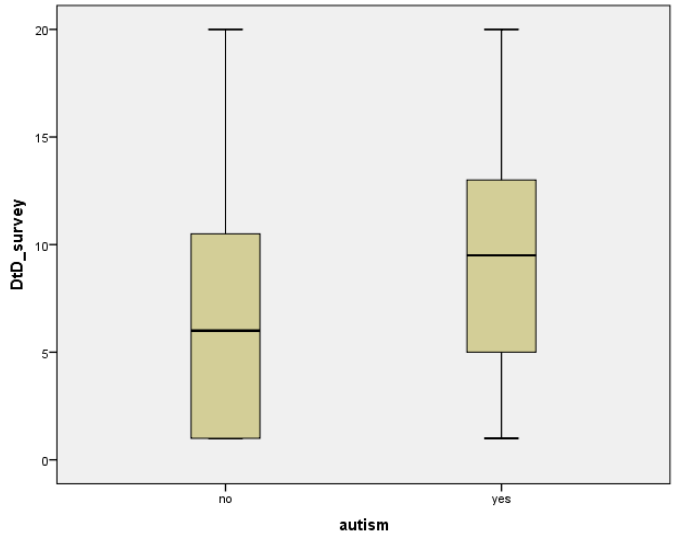


Figure: Boxplots for Draws to Decision Survey Task– TD group and ASC Group

Tests for Normality for Distribution of Scores on Continuous Variables: Kolmogorov-Smirnov Test and Q-Q Plots

Tests of Normality

		Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	autism	Statistic	df	Sig.	Statistic	df	Sig.
GPTS_total	no	.236	64	.000	.710	64	.000
	yes	.204	38	.000	.838	38	.000
SIAS_total	no	.151	64	.001	.935	64	.002
	yes	.078	38	.200*	.961	38	.203
AQ50_sysfactor	no	.111	64	.047	.953	64	.015
	yes	.138	38	.066	.955	38	.126
DtD_beads	no	.174	64	.000	.876	64	.000
	yes	.131	38	.097	.918	38	.009
DtD_survey	no	.238	64	.000	.836	64	.000
	yes	.095	38	.200*	.937	38	.034
confidence beads all	no	.198	64	.000	.911	64	.000
	yes	.120	38	.187	.979	38	.685
confidence survey all	no	.152	64	.001	.772	64	.000
	yes	.127	38	.129	.944	38	.055
total time beads	no	.287	64	.000	.387	64	.000
	yes	.131	38	.097	.883	38	.001
total time survey	no	.292	64	.000	.388	64	.000
	yes	.131	38	.099	.883	38	.001

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Significant values were returned on the K-S test for all continues variables measured in the TD group and for paranoia scores in the ASC group. Visual inspection of Q-Q plots and histograms confirmed that the data violated assumptions of normality.

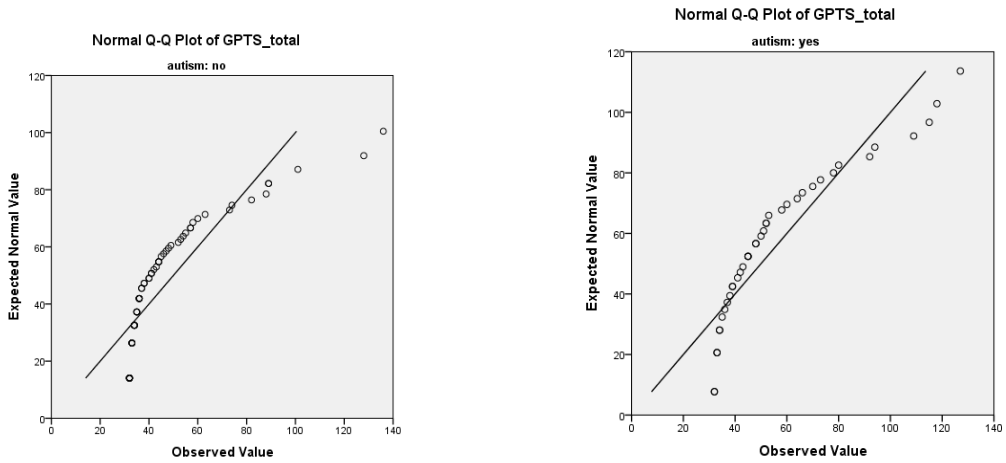


Figure: Normal Q-Q Plots for GPTS – TD group and ASC Group

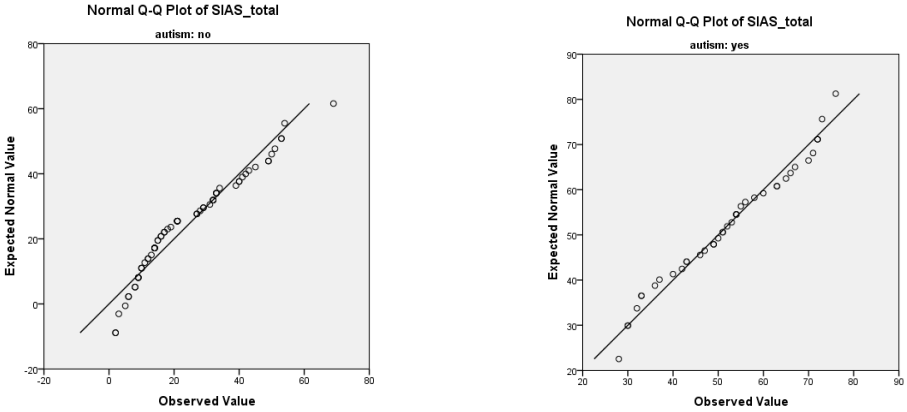


Figure: Normal Q-Q Plots for SIAS – TD group and ASC Group

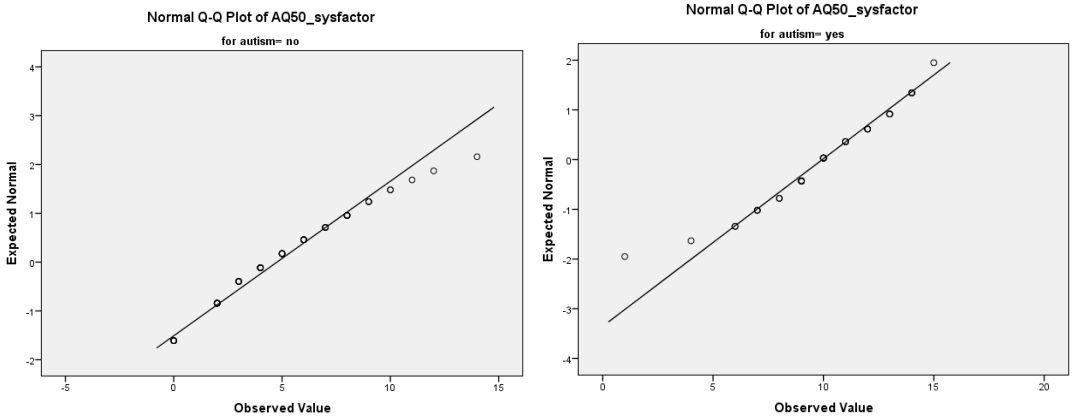


Figure: Normal Q-Q Plots for AQ50 – TD group and ASC Group

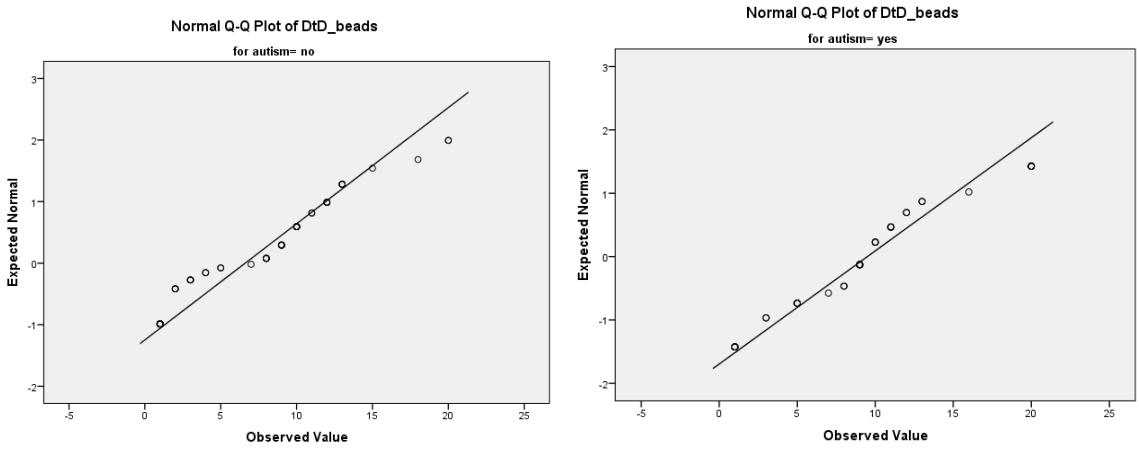


Figure: Normal Q-Q Plots for Draws to Decision on Beads Task – TD group and ASC Group

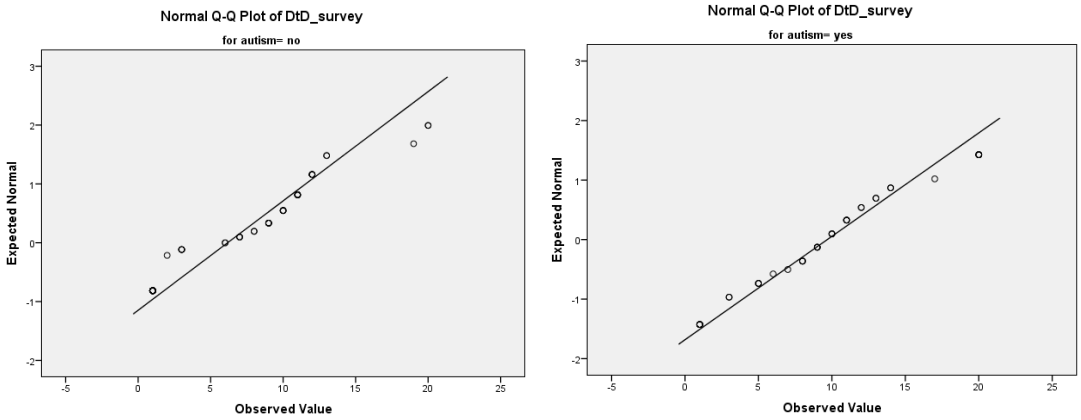


Figure: Normal Q-Q Plots for Draws to Decision on Survey Task – TD group and ASC Group

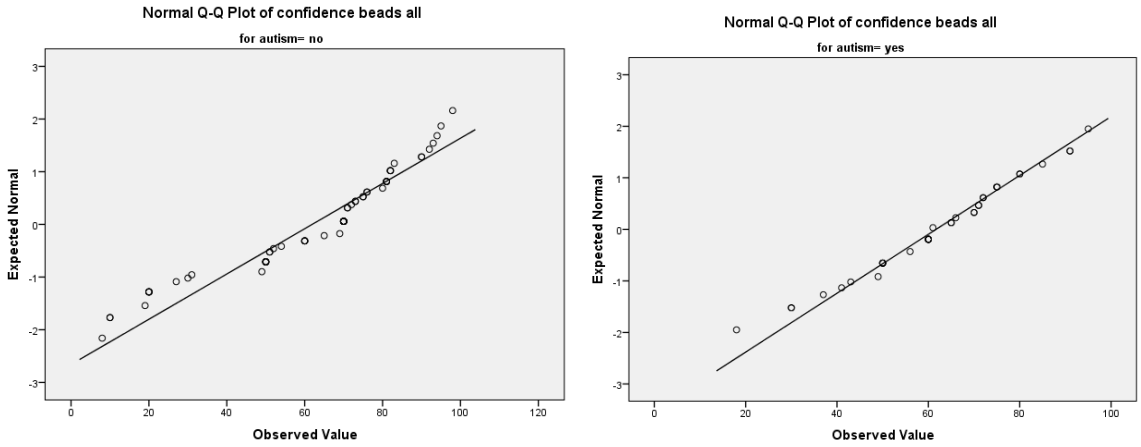


Figure: Normal Q-Q Plots for Confidence Beads Task – TD group and ASC Group

Tests of Homogeneity of Variance on Scores Between Groups: Levene's Test

Test of Homogeneity of Variance

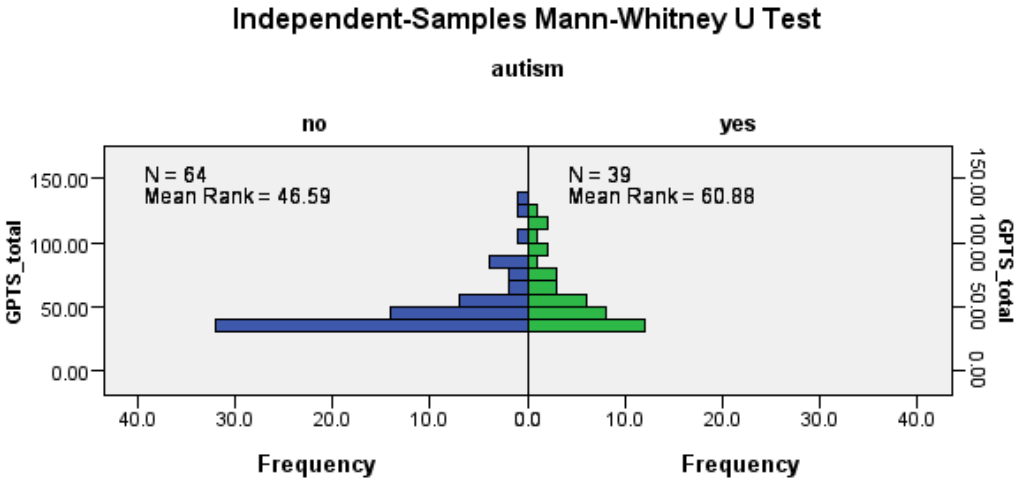
		Levene Statistic	df1	df2	Sig.
GPTS_total	Based on Mean	.997	1	100	.321
	Based on Median	.795	1	100	.375
	Based on Median and with adjusted df	.795	1	99.776	.375
	Based on trimmed mean	1.050	1	100	.308
SIAS_total	Based on Mean	1.620	1	100	.206
	Based on Median	.810	1	100	.370
	Based on Median and with adjusted df	.810	1	96.288	.370
	Based on trimmed mean	1.458	1	100	.230
AQ50_sysfactor	Based on Mean	.694	1	100	.407
	Based on Median	.554	1	100	.458
	Based on Median and with adjusted df	.554	1	99.838	.458
	Based on trimmed mean	.609	1	100	.437
DtD_beads	Based on Mean	.724	1	100	.397
	Based on Median	.769	1	100	.383
	Based on Median and with adjusted df	.769	1	87.968	.383
	Based on trimmed mean	.786	1	100	.378
DtD_survey	Based on Mean	.198	1	100	.657
	Based on Median	.189	1	100	.665
	Based on Median and with adjusted df	.189	1	88.582	.665
	Based on trimmed mean	.200	1	100	.656
confidence beads all	Based on Mean	3.814	1	100	.054
	Based on Median	1.456	1	100	.230
	Based on Median and with adjusted df	1.456	1	87.465	.231
	Based on trimmed mean	3.396	1	100	.068
confidence survey all	Based on Mean	.446	1	100	.506
	Based on Median	.375	1	100	.542
	Based on Median and with adjusted df	.375	1	88.528	.542
	Based on trimmed mean	.379	1	100	.540
total time beads	Based on Mean	.108	1	100	.743

	Based on Median	.167	1	100	.684
	Based on Median and with adjusted df	.167	1	75.667	.684
	Based on trimmed mean	.173	1	100	.679
total time survey	Based on Mean	.103	1	100	.749
	Based on Median	.157	1	100	.692
	Based on Median and with adjusted df	.157	1	75.575	.693
	Based on trimmed mean	.163	1	100	.687

Variances were found to be equal between groups on all continuous variables, with all p values for Leven's test > .05 in both groups.

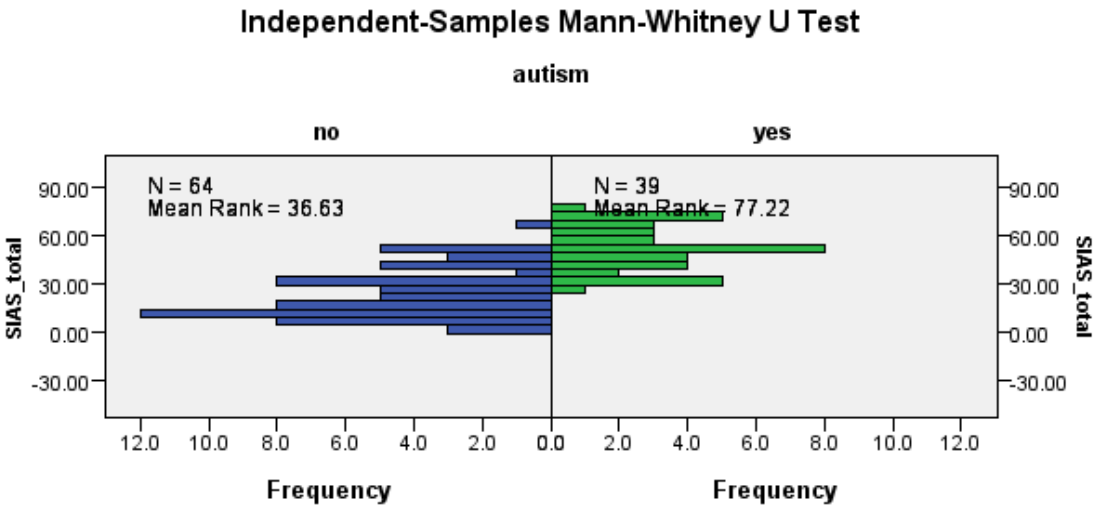
Between-Group Comparisons for Clinical Measures

Paranoia scores (GPTS)



Total N	103
Mann-Whitney U	1,594.500
Wilcoxon W	2,374.500
Test Statistic	1,594.500
Standard Error	146.918
Standardized Test Statistic	2.358
Asymptotic Sig. (2-sided test)	.018

Social Anxiety Scores (SIAS)



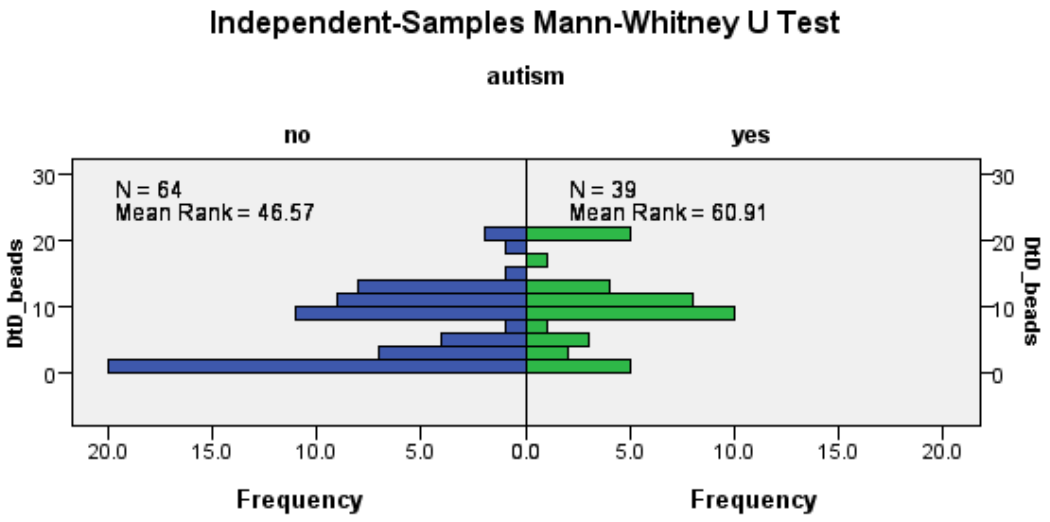
Total N	103
Mann-Whitney U	2,231.500
Wilcoxon W	3,011.500
Test Statistic	2,231.500
Standard Error	147.026
Standardized Test Statistic	6.689
Asymptotic Sig. (2-sided test)	.000

Hypothesis 1: SPSS Output

Hypothesis 1: The ASC group will differ from the TD group in number of draws to decision on both versions of the task.

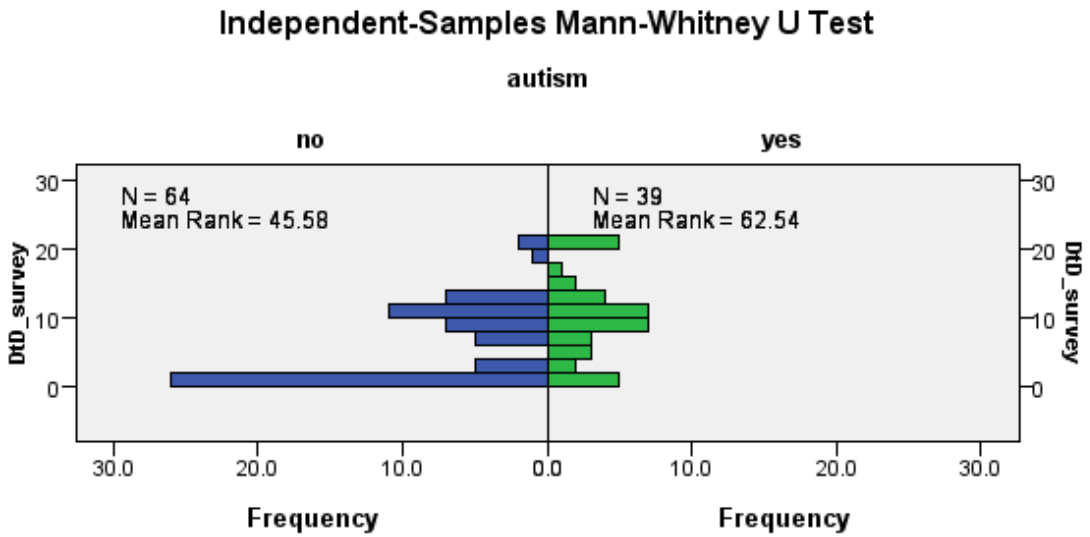
Error bars

Draws to Decision on the Beads Task for ASC and TD Groups



Total N	103
Mann-Whitney U	1,595.500
Wilcoxon W	2,375.500
Test Statistic	1,595.500
Standard Error	145.602
Standardized Test Statistic	2.387
Asymptotic Sig. (2-sided test)	.017

Draws to Decision on the Survey Task for ASC and TD Groups



Total N	103
Mann-Whitney U	1,659.000
Wilcoxon W	2,439.000
Test Statistic	1,659.000
Standard Error	144.827
Standardized Test Statistic	2.838
Asymptotic Sig. (2-sided test)	.005

Hypothesis 2: SPSS Output

Hypothesis 2: The proportion of individuals showing a JTC bias will differ between the TD and ASC groups.

Chi Square for Autism * JTC bias

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	7.958[a]	1	.005		
Continuity Correction[b]	6.745	1	.009		
Likelihood Ratio	7.849	1	.005		
Fisher's Exact Test				.007	.005
Linear-by-Linear Association	7.877	1	.005		
N of Valid Cases	98				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 11.70.

b. Computed only for a 2x2 table

JTC bias on beads task * autism Crosstabulation

			autism		
			no	yes	Total
JTC bias on beads taks	no	Count	41$_a$	34$_b$	75
		Expected Count	46.6	28.4	75.0
		% within JTC bias on beads taks	54.7%	45.3%	100.0%
		% within autism	64.1%	87.2%	72.8%
		Standardized Residual	-.8	1.1	
	yes	Count	23$_a$	5$_b$	28
		Expected Count	17.4	10.6	28.0
		% within JTC bias on beads taks	82.1%	17.9%	100.0%
		% within autism	35.9%	12.8%	27.2%
		Standardized Residual	1.3	-1.7	
Total		Count	64	39	103
		Expected Count	64.0	39.0	103.0
		% within JTC bias on beads taks	62.1%	37.9%	100.0%
		% within autism	100.0%	100.0%	100.0%

Each subscript letter denotes a subset of autism categories whose column proportions do not differ significantly from each other at the .05 level.

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	6.542[a]	1	.011		
Continuity Correction[b]	5.426	1	.020		
Likelihood Ratio	7.065	1	.008		
Fisher's Exact Test				.012	.008
Linear-by-Linear Association	6.479	1	.011		
N of Valid Cases	103				

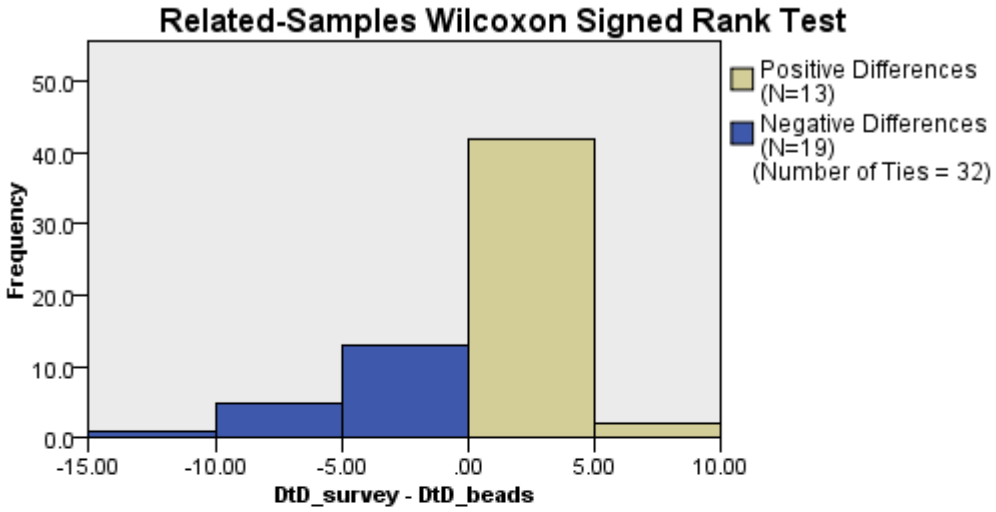
a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 10.60.

b. Computed only for a 2x2 table

Hypothesis 3: SPSS Output

Hypothesis 3: Task design will affect performance for the TD group but not the ASC group, with the TD group predicted to show hastier decision-making (less DtD) on the emotionally salient version of the task (survey task).

SPPS output for TD group



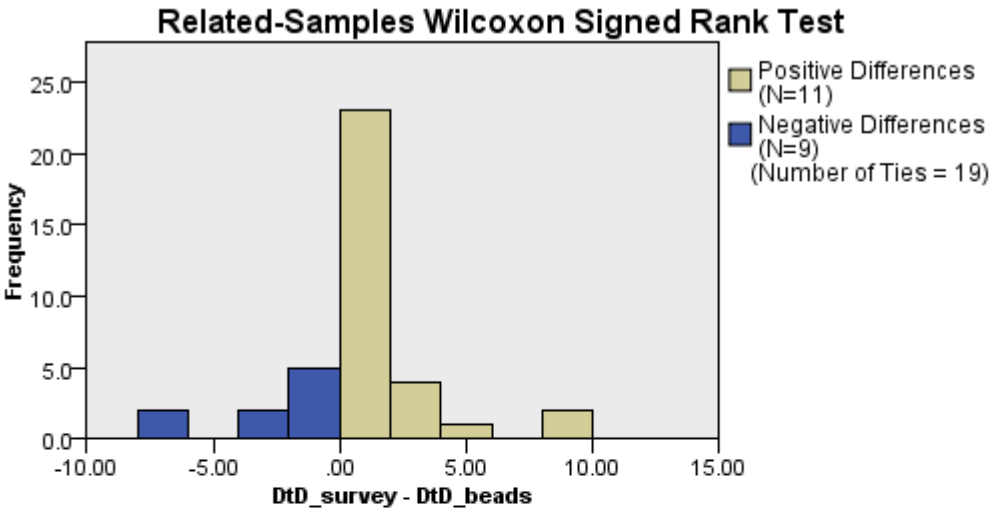
Total N	64
Test Statistic	220.000
Standard Error	53.014
Standardized Test Statistic	-.830
Asymptotic Sig. (2-sided test)	.407

Effect size calculation for TD group

r= standardised test statistic= -.830 divided by square root of number of observations (128)=11.314

r=-.007

SPSS output for ASC group



Total N	39
Test Statistic	110.000
Standard Error	26.636
Standardized Test Statistic	.188
Asymptotic Sig. (2-sided test)	.851

Effect size calculation for ASC group

r= standardised test statistic= .851 divided by square root of number of observations (78)=8.832

r=-.006

Hypothesis 4: SPSS Output

Hypothesis 4: Paranoia will be associated with draws to decision on the beads task in both groups.

Test: Spearman's Bivariate Correlation

autism						GPTS_total	DtD_beads
no	Spearman's rho	GPTS_total	Correlation Coefficient			1.000	-.170
			Sig. (2-tailed)			.	.180
			N			64	64
			Bootstrap[c]	Bias		.000	.008
				Std. Error		.000	.129
				BCa 95% Confidence Interval	Lower	.	-.418
					Upper	.	.120
		DtD_beads	Correlation Coefficient			-.170	1.000
			Sig. (2-tailed)			.180	.
			N			64	64
			Bootstrap[c]	Bias		.008	.000
				Std. Error		.129	.000
				BCa 95% Confidence Interval	Lower	-.418	.
					Upper	.120	.
yes	Spearman's rho	GPTS_total	Correlation Coefficient			1.000	-.135
			Sig. (2-tailed)			.	.413
			N			39	39
			Bootstrap[c]	Bias		.000	.001
				Std. Error		.000	.169
				BCa 95% Confidence Interval	Lower	.	-.461
					Upper	.	.216
		DtD_beads	Correlation Coefficient			-.135	1.000
			Sig. (2-tailed)			.413	.
			N			39	39
			Bootstrap[c]	Bias		.001	.000
				Std. Error		.169	.000
				BCa 95% Confidence Interval	Lower	-.461	.
					Upper	.216	.

c. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples

Hypothesis 5: SPSS Output

Hypothesis 5: Scores on the systemising traits factor (AQ50) will be associated with draws to decisions on the beads task in both groups.

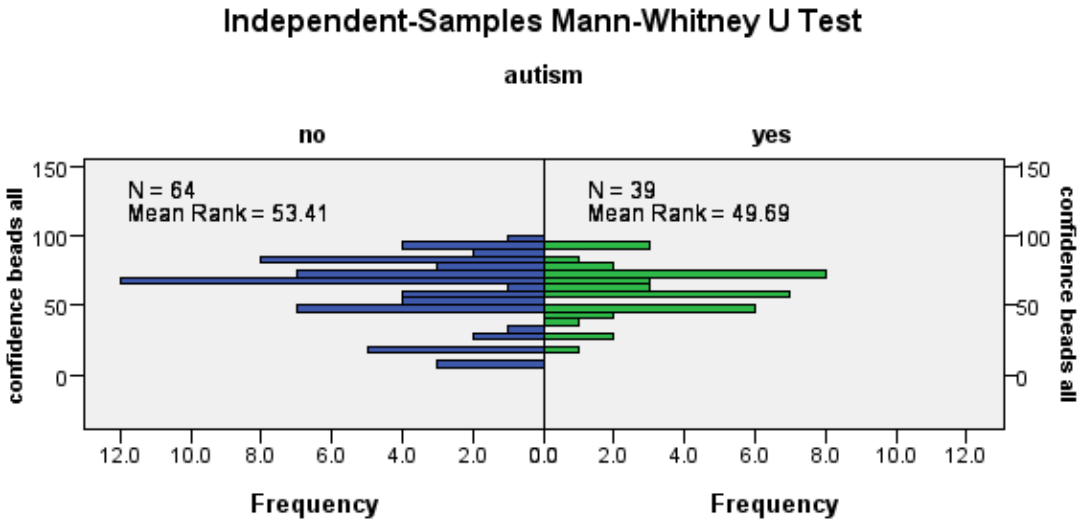
Test: Spearman's Bivariate Correlation

autism						AQ50_sysfactor	DtD_beads
no	Spearman's rho	AQ50_sysfactor	Correlation Coefficient			1.000	-.060
			Sig. (2-tailed)			.	.637
			N			64	64
			Bootstrap[c]	Bias		.000	.001
				Std. Error		.000	.130
				BCa 95% Confidence Interval	Lower	.	-.294
					Upper	.	.196
		DtD_beads	Correlation Coefficient			-.060	1.000
			Sig. (2-tailed)			.637	.
			N			64	64
			Bootstrap[c]	Bias		.001	.000
				Std. Error		.130	.000
				BCa 95% Confidence Interval	Lower	-.294	.
					Upper	.196	.
yes	Spearman's rho	AQ50_sysfactor	Correlation Coefficient			1.000	-.303
			Sig. (2-tailed)			.	.061
			N			39	39
			Bootstrap[c]	Bias		.000	.000
				Std. Error		.000	.146
				BCa 95% Confidence Interval	Lower	.	-.564
					Upper	.	-.014
		DtD_beads	Correlation Coefficient			-.303	1.000
			Sig. (2-tailed)			.061	.
			N			39	39
			Bootstrap[c]	Bias		.000	.000
				Std. Error		.146	.000
				BCa 95% Confidence Interval	Lower	-.564	.
					Upper	-.014	.

c. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples

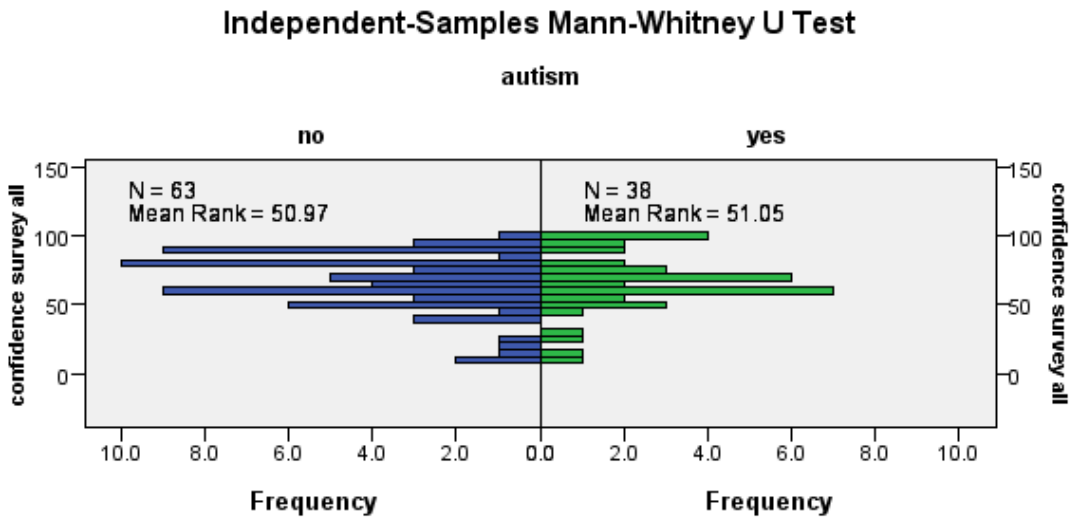
SPSS Output for Posthoc Exploration of Task Performance Variables

The Mann-Witney U test was used for all between-group comparisons.



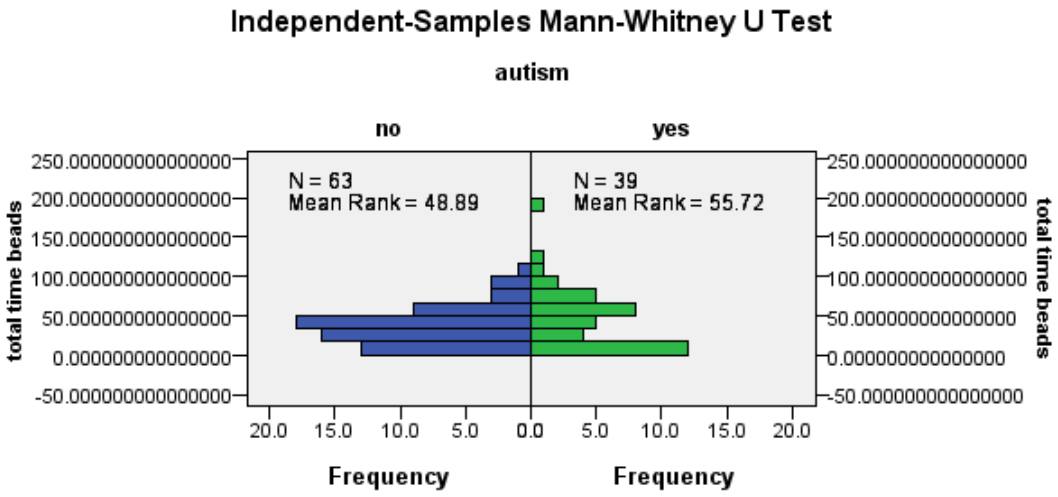
Total N	103
Mann-Whitney U	1,158.000
Wilcoxon W	1,938.000
Test Statistic	1,158.000
Standard Error	146.738
Standardized Test Statistic	-.613
Asymptotic Sig. (2-sided test)	.540

Figure: *Confidence Ratings for Beads Task*



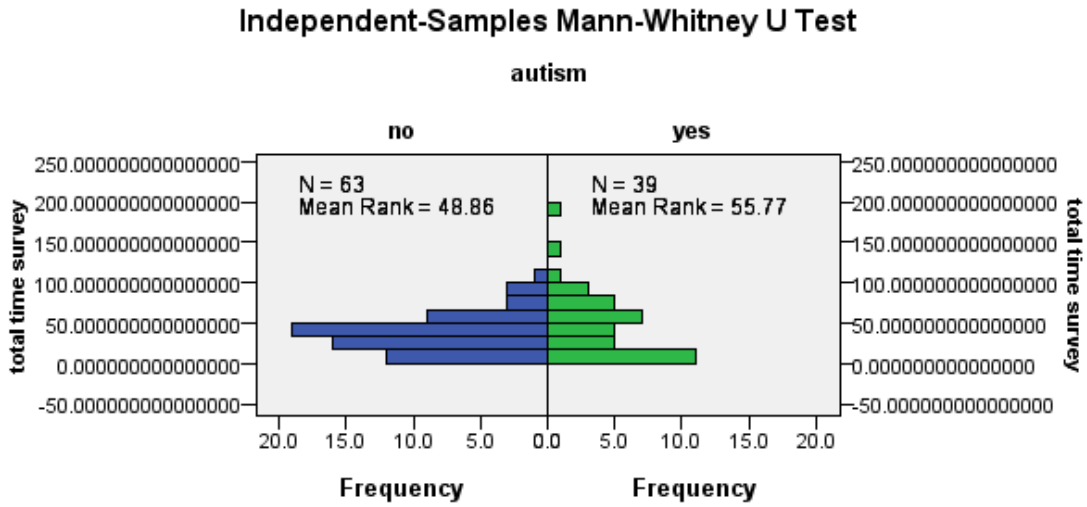
Total N	101
Mann-Whitney U	1,199.000
Wilcoxon W	1,940.000
Test Statistic	1,199.000
Standard Error	142.416
Standardized Test Statistic	.014
Asymptotic Sig. (2-sided test)	.989

Figure: *Confidence ratings for Survey Task*



Total N	102
Mann-Whitney U	1,393.000
Wilcoxon W	2,173.000
Test Statistic	1,393.000
Standard Error	145.221
Standardized Test Statistic	1.133
Asymptotic Sig. (2-sided test)	.257

Figure: *Time in Seconds for Completing the Beads Task*



Total N	102
Mann-Whitney U	1,395.000
Wilcoxon W	2,175.000
Test Statistic	1,395.000
Standard Error	145.221
Standardized Test Statistic	1.147
Asymptotic Sig. (2-sided test)	.252

Figure: *Time in Seconds for Completing the Survey Task*

Chi Square Tests for Correct vs Incorrect Choice of Jar /Survey by Group

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
correct jar * autism	103	100.0%	0	0.0%	103	100.0%
correct survey * autism	103	100.0%	0	0.0%	103	100.0%

Crosstab

			autism		
			no	yes	Total
correct jar	0	Count	6	5	11
		Expected Count	6.8	4.2	11.0
		% within correct jar	54.5%	45.5%	100.0%
		% within autism	9.4%	12.8%	10.7%
	1	Count	58	34	92
		Expected Count	57.2	34.8	92.0
		% within correct jar	63.0%	37.0%	100.0%
		% within autism	90.6%	87.2%	89.3%
Total		Count	64	39	103
		Expected Count	64.0	39.0	103.0
		% within correct jar	62.1%	37.9%	100.0%
		% within autism	100.0%	100.0%	100.0%

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)	Point Probability
Pearson Chi-Square	.302[a]	1	.583	.744	.405	
Continuity Correction[b]	.049	1	.826			
Likelihood Ratio	.296	1	.586	.744	.405	
Fisher's Exact Test				.744	.405	
Linear-by-Linear Association	.299[c]	1	.585	.744	.405	.216
N of Valid Cases	103					

a. 1 cells (25.0%) have expected count less than 5. The minimum expected count is 4.17.

b. Computed only for a 2x2 table

c. The standardized statistic is -.546.

Crosstab

			autism		
			no	yes	Total
correct survey	0	Count	9	4	13
		Expected Count	8.1	4.9	13.0
		% within correct survey	69.2%	30.8%	100.0%
		% within autism	14.1%	10.3%	12.6%
	1	Count	55	35	90
		Expected Count	55.9	34.1	90.0
		% within correct survey	61.1%	38.9%	100.0%
		% within autism	85.9%	89.7%	87.4%
Total		Count	64	39	103
		Expected Count	64.0	39.0	103.0
		% within correct survey	62.1%	37.9%	100.0%
		% within autism	100.0%	100.0%	100.0%

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)	Point Probability
Pearson Chi-Square	.318[a]	1	.573	.762	.406	
Continuity Correction[b]	.067	1	.796			
Likelihood Ratio	.326	1	.568	.762	.406	
Fisher's Exact Test				.762	.406	
Linear-by-Linear Association	.315[c]	1	.574	.762	.406	.212
N of Valid Cases	103					

a. 1 cells (25.0%) have expected count less than 5. The minimum expected count is 4.92.

b. Computed only for a 2x2 table

c. The standardized statistic is .561.

Chi Square Test for Presence of Persecutory Ideation (single item from PDI)

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Persecutory Ideation present * autism	98	100.0%	0	0.0%	98	100.0%

Persecutory Ideation present * autism Crosstabulation

			autism		
			no	yes	Total
Persecutory Ideation present	0	Count	48_a	19_b	67
		Expected Count	41.7	25.3	67.0
		% within Persecutory Ideation present	71.6%	28.4%	100.0%
		% within autism	78.7%	51.4%	68.4%
		Standardized Residual	1.0	-1.3	
	1	Count	13_a	18_b	31
		Expected Count	19.3	11.7	31.0
		% within Persecutory Ideation present	41.9%	58.1%	100.0%
		% within autism	21.3%	48.6%	31.6%
		Standardized Residual	-1.4	1.8	
Total		Count	61	37	98
		Expected Count	61.0	37.0	98.0
		% within Persecutory Ideation present	62.2%	37.8%	100.0%
		% within autism	100.0%	100.0%	100.0%

Each subscript letter denotes a subset of autism categories whose column proportions do not differ significantly from each other at the .05 level.

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	7.958[a]	1	.005		
Continuity Correction[b]	6.745	1	.009		
Likelihood Ratio	7.849	1	.005		
Fisher's Exact Test				.007	.005
Linear-by-Linear Association	7.877	1	.005		
N of Valid Cases	98				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 11.70.

b. Computed only for a 2x2 table